

Market Position Statement for Individuals, Families, and Carers Living with Autism

A Sense of Direction

Northamptonshire County Council wishes to stimulate a diverse market, offering people a real choice of provision in relation to care and support. This may come from existing providers, other local businesses, those who do not currently work in the authority, or from new business start-ups.

Financial costings, customer numbers, and future projections are a snapshot and are, therefore, correct at the time of writing. Data regarding increases within specific geographical areas will be added to this document when available.

Northamptonshire County Council's (NCC) Market Position Statement (MPS) for Individuals, Families, and Carers living with Autism will focus exclusively on adults of working age. However, in order to contextualise the lifelong nature of the Autism journey, a section will make reference to current data relating to children and young people. Separate Market Position Statements will address Learning Disabilities and Mental Health.

Throughout this document, the term 'autism' is used to describe all diagnostic profiles including Asperger Syndrome (AS) and Autistic Spectrum Disorder (ASD). The term also takes into account co existing conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and Pathological Demand Avoidance (PDA).

Key Messages

Autism is a lifelong developmental condition that affects how people perceive the world and interact with others. Autism is not an illness or disease. Individuals living with Autism experience the world differently and often view Autism as a fundamental aspect of their identity.

Autism is referred to as a spectrum condition. Individuals living with Autism share certain difficulties, but are affected in different ways. All individuals and families living with Autism learn and develop. With the right sort of support, all can be helped to live more fulfilling lives of their own choosing.

Living with Autism is often stressful and stress is linked to episodes of mental and emotional ill health. In particular, individuals living with Autism experience heightened levels of anxiety and depression. Late adolescence and early adult life are times of increased vulnerability.

The long term nature of Autism, and any variation in the severity of impact, means that the needs for individuals and families living with autism are not directly comparable with people requiring care and support for other reasons.

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 fulltime, ongoing service provision but who may require only occasional support at certain times.

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 living with, and affected by, Autism are unlikely to be in receipt of appropriate service provision. Evidence relating to the prevalence of Autism within BaME communities is inconsistent.

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>

Key Messages for Providers

Vision & Overview

Adult Social Care would like to support all people, where possible, to remain in their own homes or move into independent housing. However, if specialist accommodation is required, we want to provide suitable homes to meet the individuals assessed needs.

It is recognised that there are common interests and inter-dependencies that exist between NHS, Social Care, and Housing and Planning partners therefore overarching strategies should identify current and future needs to highlight where there is overlap and opportunities to work together to benefit individuals and families living with Autism.

NCC is committed to a progression model across all client groups, including those who may traditionally have not been considered as having potential for sustainable personal improvement in independence, supported living, and wellbeing. This means that all new and existing service provision will be required to identify progression goals.

Accommodation needs to be designed around people's needs and properties must be in locations close to educational and employment opportunities. For all new and reconfigured supported living provision, NCC will be asking for a minimum standard of Assistive Technology to allow young people to perform tasks for themselves to build confidence and independence without having to rely on support care staff.

Assistive Technology enables personalised care, choice, dignity and control. It give providers and service users the flexibility to operate unsupported at times whilst reassuring all parties that help will be alerted if problems arise. This supports an increase in 'home alone' time where desired, reduces hours of support needed during the day, and also, significantly, at night, both in relation to 'waking nights' and 'sleep-in' support.

Demographic

Autism doesn't just affect children. A child living with Autism eventually becomes an adult living with Autism.

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

Independent and supported accommodation remains a significant issue, as there are currently insufficient options for individuals living with Autism. 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 young people moving to adult services, existing residential placements coming to an end, and individuals with Autism living with elderly parents who are no longer able to provide the support required. An increase in Supported Living provision will improve opportunities for the people to live in suitable accommodation based on their current and potential future needs.

Specialist accommodation and service provision is also required for Individuals returning to Northamptonshire from out of county hospital, residential, and educational placements. Currently there are 13 individuals with a primary diagnosis of with Autism within a cohort of 27 placed in specialist educational facilities.

Introduction

Traditionally, Autism has not been viewed as a stand-alone service area. Individuals, families, and carers living with Autism, who are eligible for care and support, have usually been identified as having a primary support need relating to either a learning disability or mental ill health. However, this has now begun to change. As a result, refocussed service provision has improved outcomes and remained cost neutral. In some cases significant cost savings have been reported.

“Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England (2010)”, and subsequent statutory guidance, sets out to ensure that individuals and families living with autism are able to benefit fully from mainstream statutory and non-statutory services across all agencies by improving access .While this does not necessarily guarantee specialist Autism services, it does mean that providers of all levels of support are expected to:

- understand the needs of individuals and families living with autism
- achieve high levels of autism awareness
- train staff appropriately

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/301492/Think_Autism_-_Autism_Strategy-colour_contrast_version.pdf

Northamptonshire County Council (NCC) recognises that it needs to better understand how it can influence and support the local marketplace to realize the above whilst achieving better outcomes and value for money for individuals, families, and carers living with Autism. NCC is keen to actively engage, and work in partnership, with all stakeholders in order to identify creative, innovative and cost-effective ways to meet need appropriately.

As a result of Autism themed workshops and a period of wider consultation, individuals, families, and carers living with Autism have told us what they need including, a trained and skilled workforce, services that offer continuity and consistency of care, and an efficient and accessible diagnostic service. They consistently highlight the needs around housing, employment, meaningful day time opportunities, the aging carer population and more recently, the lack of seamless service provision between adolescence and adulthood.

NCC's Market Position Statement (MPS) is an important part of an ongoing journey, as it helps identify what the future demand for care and support for individuals and families living with Autism might look like. It is an attempt to signal to the market, likely future demand in its broadest sense, whilst recognising the developing national position on public sector financing which makes it impossible to make definitive statements about future commissioning intentions.

However, the MPS begins the process of initiating conversations with a wide range of stakeholders and contains information and analysis of benefit to providers of support services.

In practical terms the Council and its partners will seek to make best use of community assets by integrating them wherever possible with formal care and support services and utilising the existing spend of the Council and partners on preventative services in a more co-ordinated way.

As a result:

- NCC is transparent about the way it intends to strategically commission and influence services in the future
- Market information can be pooled and shared,
- Services can be developed that individuals and families living with Autism need and want.

It must however be remembered that much of the need for care and support continues to be met by families, friends or other informal carers, who, in order to continue, require:

- Ease of access to wide ranging collaborative community networks and third sector organisations
- Effective and wide ranging universal services, all of which promote prevention, thereby minimising the need for a crisis focussed response
- Access to good quality information, advice and advocacy

There is a need to stimulate a diverse market in order to provide an improved range of continuing education, employment and accommodation (both specialist housing options and "lifetime homes") options for both younger and older adults.

Given that so many Adults living with Autism are not eligible for funding from the local authority, there is a need to improve access to the services and support individuals may need to live independently.

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 NCC cannot provide service provision in isolation. As a result, the development and expansion of the Autism Community and Third Sector 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 the third sector so that it has opportunity to influence policy and decision making
- Development of robust and effective third sector infrastructure support

National Prevalence

Autism in adults is much more common than many people think. Recently, data from surveys undertaken during 2007 and 2014 was combined to generate a larger sample for analysis. Taking into account sampling error, it is estimated that if all adults in the population had been tested, the proportion identified with Autism would probably reach 1.3% (more than 700,000 adults). If you include their families and carers, it is estimated that Autism is a part of daily life for 2.8 million people. 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.

Consistent with other research, estimated rates of Autism in adults are:

- Higher in men than women (five times as many males as females are diagnosed)
- Associated with level of educational qualification, with rates being higher among people with no qualifications.

Research findings also suggest that:

- Between 48% - 56% of individuals living with Autism people do not have a learning disability.
- Seventy per cent of adults living with Autism state that they are not getting the help they need
- In the UK, only 16% of adults living with Autism are in full-time paid employment, and only 32% are in some kind of paid work.
- Only 10% of adults living with Autism receive employment support but 53% say they want it.

Of note, around one in three adults living with Autism report experiencing mental health difficulties due to a lack of support. However, adults living with Autism appeared to be no more likely than other adults to make use of treatment or services for mental or emotional problems. In terms of future service provision, research suggests estimates of approximately 140,000 children living with autism in the UK. This is a prevalence rate of 0.9% or 90 in 10,000. The average age of diagnosis is five.

Across Northamptonshire, allocation details are as follows:

Children with Autism/Asperger's Disability

Team	Child Status			Grand Total
	CIN	Child Protection Plan	LAC	
Disabled Children's Team	84	6	18	108
LAC/Leaving Care Teams	8	0	19	27
Safeguarding Teams	25	10	10	45
Grand Total	117	16	47	180

*CIN (Child in Need), LAC (Looked After Child)

Around 70 per cent of children living with autism are in mainstream schools. However, 63% of children are not in the kind of school their parents believe would best support them. Furthermore, 17% of autistic children have been suspended from school; 48% of these had been suspended three or more times; 4% had been expelled from one or more schools.

When compared to White British pupils, the prevalence of diagnosed autism in pupils of Asian heritage is 50% lower. Meanwhile, the prevalence of Autism related speech, language and communication needs in Black pupils was almost twice as high as their White British counterparts

Locally, the Pupil Level Annual School Census 2010 (PLASC) showed that out of the entire school population in Northants there were 443 (0.9%) pupils aged 0-19, identified as living with Autism via a Statement of Special Educational Needs or School Action Plus. This figure is clearly similar to the prevalence rate identified in adults. Most recent SEND data (2017) identifies 1404 children living with Autism. 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

For a comprehensive overview of Special Educational Needs and Disability provision (SEND) follow the link below:

<http://www3.northamptonshire.gov.uk/councilservices/children-families-education/SEND/Pages/default.aspx>

For a comprehensive overview of the Joint Strategic Needs assessment (JNSA) relating to children follow the link below:

<https://www.northamptonshireanalysis.co.uk/jsna/childrenjsna>

Local Context

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).

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	7	35	2	4	8	49
	Mental Health Support		16	1	1		18
	Personal Care Support		2	1		1	4
	Support for Social Isolation or Other Support		3				3
LD - Aspergers Syndrome/High Functioning Autism Total		7	56	4	5	9	74

Autism Type	Long Term Primary Support Reason	Day Care	Direct Payments	Home Care	Residential	Supported Living	Total
LD - Aspergers Syndrome/High Functioning Autism	Learning Disability Support	72,889	655,121	21,902	229,347	76,098	1,055,356
	Mental Health Support		96,874	4,002	47,450		148,326
	Personal Care Support		16,532	3,096		27,268	46,897
	Support for Social Isolation or Other Support		30,145				30,145
LD - Aspergers Syndrome/High Functioning Autism Total		72,889	798,672	29,000	276,797	103,366	1,280,724

Raw data for 2017/18 shows a 6.5% increase in customers (rising 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

Autism Type	Long Term Primary Support Reason	Day Care	Direct Payments	Home Care	Residential	Supported Living	Total
LD - Aspergers Syndrome/High Functioning Autism	Learning Disability Support	36,837	721,986	21,635	131,129	287,757	1,199,345
	Mental Health Support		112,408		47,450		159,858
	No Relevant Long Term Support Reason				61,737		61,737
	Personal Care Support		27,520	229		27,268	55,018
	Support for Social Isolation or Other Support		47,240		4,521		51,761
LD - Aspergers Syndrome/High Functioning Autism Total		36,837	909,154	26,386	240,317	315,025	1,527,719

In Northamptonshire, based on an estimated prevalence in those categorised as 'high functioning' (50% of all adults 18-64 living with autism), and the reported rate of 30% experiencing a mental health problem, we might expect at least 275 adults living Autism to have a co-occurring mental health problem such as depression or anxiety.

When compared to the 2016/17 figures for the general Learning Disability population (where, although diagnosed, Autism is not the Primary Support Need) numbers increase dramatically:

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	41	164	6	1	1	46	38	246
	Mental Health Support			2	1					3
	No Relevant Long Term Support Reason			2	1					2
	Personal Care Support		1	5				1	3	8
	Support for Social Isolation or Other Support		1	7					2	7
LD - Autism (excl Aspergers Syn/High Functioning) Total		7	43	180	8	1	1	47	43	266

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

Raw data for 2017/18 shows a 10.9% increase in customers (rising to 295) with costs up by 19%

Autism Type	Long Term Primary Support Reason	Campus Reprovision	Day Care	Direct Payments	Home Care	Nursing	Rehab + Respite	Residential	Supported Living	Total
LD - Autism (excl Aspergers Syn/High Functioning)	Learning Disability Support	933,298	632,542	4,065,164	169,948	71,170	11,542	4,097,346	1,703,042	11,684,051
	Mental Health Support			8,599	1,469					10,068
	No Relevant Long Term Support Reason			4,981	4,521					9,502
	Personal Care Support		24,825	66,250				39,047	48,703	178,825
	Support for Social Isolation or Other Support		6,609	84,580					21,279	112,468
LD - Autism (excl Aspergers Syn/High Functioning) Total	933,298	663,975	4,229,575	175,937	71,170	11,542	4,136,393	1,773,024	11,994,913	

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	1,036,911	655,961	4,434,013	296,768	110,590	31,839	4,950,711	2,499,072	14,015,865
	Mental Health Support			14,852	435					15,287
	No Relevant Long Term Support Reason			5,459						5,459
	Personal Care Support		8,846	64,744				39,058	50,754	163,402
	Support for Social Isolation or Other Support		13,430	78,847					23,755	116,031
LD - Autism (excl Aspergers Syn/High Functioning) Total	1,036,911	678,236	4,597,915	297,203	110,590	31,839	4,989,769	2,573,581	14,316,044	

The Adult Mental Health and Individual Package of Care (IPC) Teams have records indicating the provision of services to 82 adults diagnosed with Autism (including so called High Functioning Autism). 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:

- Forty one (41) community packages (including CCP and/or day services)
- One (1) full time nursing placement
- Five (5) full time residential placements
- Thirty one (31) supported accommodation placements

The remaining four (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)

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 individuals living with autism this can be a long and challenging process. Coordinating choices for suitable accommodation, as well as identifying the necessary support services can be complicated. Choice and control remain aspirational rather than the reality. In terms of current Supported Living options, Individuals living with Autism account for 8.4% of placements.

	Number of supported living properties
Corby	8 properties
Daventry	
East Northamptonshire	8 properties
Kettering	20 properties
Northampton	76 properties
South Northants	11 properties
Wellingborough	24 properties
Total	147 properties

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.

Supporting young people with a disability through their transition into adulthood is key to a successful, fulfilling and meaningful experience in their early adult life.

The Council wants to ensure that, during this period of change, young people and their families are fully supported to make the right choices about their care, support and housing.

Trend data over the past 3 years shows on average 38.6 clients aged 16 and 17 who are currently being supported by the Transitions Team in ASC.

Transitions Clients				
	13-14	14-15	15-16	Average
17 year olds	49	34	33	38.6
16 year olds	44	32	34	36.6

In order to understand the types of accommodation and services needed for these young 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. This could be as a result of remodelling existing provision or new build schemes.

Adults living with autism 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. Original estimates (2009) suggested a shortfall in excess of 10 000 homes. Therefore, many adults living with autism 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 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>

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

Meanwhile, within the Children's Transforming Care cohort referrals are increasing regionally (East Midlands) and nationally by 70%. Girls account for the largest growth. If individuals are not able to return to the family home it is likely that supportive accommodation will be required.

A comprehensive strategy document, entitled 'Building the Right Home: Guidance for commissioners of health and care services for children, young people and adults with learning disabilities and/or autism who display behaviour that challenges' can be accessed by following the link below:

<https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-guidance-housing.pdf>

Providers of services need to consider whether it is appropriate, in terms of equality, to set arbitrary cut offs, such as an IQ level, to determine which people with autism they will support. There are clear benefits to services of being inclusive and supporting people across the spectrum.

Community Opportunities

Investment in services that aim to tackle social exclusion among people living with autism is vital. For minimal cost, it is possible to provide weekly social opportunities based around common interests and structured activities whilst person centred support planning should focus on the identification and development of the skills individuals require to lead as independent a life as possible. For some people this means attending college to access various courses, for others it could be work placements and other day opportunities in-line with their goals and aspirations. Therefore accommodation, employment, social skills mentoring, counselling, and access to diagnostic service provision will be areas of particular interest to providers.

However, none of the above can be achieved in isolation therefore close links between providers, educational establishments, employers, and community projects should be developed.

Key commissioning intentions

In partnership with key stakeholders and Providers, NCC intends to:

Promote the development of 13-15 units of supported living per year in order to meet the estimated number of ASC funded young adults exiting the Transitions Service.

Work with local partners to push for the development of reasonable adjustments across the full range of public and community services.

Improve systems for collecting information relating to individuals living with autism in order to enable better analysis regarding needs and service uptake

Identify and promote a range of adjustments mainstream services could make to improve the employment outcomes of adults with autism.

Develop with partners, a sustainable, ongoing, strategic workforce strategy for training and raising awareness across the health, social care, voluntary sector, education, employment and criminal justice systems.

Address the barriers resulting in the likely lower diagnosis and take-up of services from minority ethnic communities, women and other disadvantaged communities.

Ensure the Autism Strategy Steering Group maintains a robust strategic vision and remains committed to delivering the Market Position Statement.

Challenges for providers

- Attracting and recruiting a sufficient number of staff into services for working age adults who have the appropriate values and behaviours.
- Ensuring that staff are retained, motivated, and supported
- Training staff to develop their knowledge and skills so that they deliver Autism specific personalised care.
- The market continues to provide limited options in terms of Autism specific accommodation. While much positive work has taken place in Northamptonshire to meet these challenges, more needs to be done.
- The number of Service users receiving help and support from the Council is remaining fairly static; however the number of people with more complex or multiple disabilities is increasing.
- Making the best use of new technology for working with individuals for example using technology to monitor service users at night instead of sleeping in staff.
- Providers may wish to consider deregistering residential care homes and providing them as supported living schemes.