

Nottingham City Council Autism Spectrum Conditions Health Needs Assessment, 2019

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1. Introduction

Autism Spectrum Conditions affect the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Autistic people can often find understanding and communicating with others challenging. They may also experience some form of hypersensitivity or hyposensitivity, for example to sound, touch, taste, smell, lights or colours. It is a spectrum of different needs and is different for every individual. Autism is a lifelong condition and people may need to use services at any time in their life.

Everyday life for some autistic people can be confusing and frightening, which in turn leads to feelings of isolation and loneliness. A lack of understanding of autistic people's complex needs can negatively influence their quality of life, relationships, support networks and job prospects.

The aim of this health needs assessment is to identify the needs of autistic people in Nottingham City and complements the Nottingham City Strategic Framework for Autism 2018-2020 that will better serve this subgroup of the population. For more information on Health Needs Assessments and the methods used to develop this report, please see Appendix A.

2. Terminology

The term autistic people, rather than people with autism, is used in this needs assessment. This choice of language is deliberate and reflects that many autistic people see their autism as a key feature of their identity rather than as a medical diagnosis. The decision to use the term autistic people reflects the adoption of this term by national and local organisations including the National Autistic Society, Autistic Nottingham and Autism East Midlands, all of whom are represented on Nottingham's Autism Strategy Group.

3. Scope and Policy context

This needs assessment will consider the needs of both children and adults with autism in Nottingham City and reflects Nottingham City Council's approach to all age disability. The assessment adopts a social model of disability, recognising that disability is caused by the way society is organised, rather than by autism itself and considers ways of removing barriers that restrict life choices for autistic people.

This health needs assessment is particularly timely given the upcoming review of the national ['Think Autism' Strategy](#) due to take place in 2019, marking ten years since the Autism Act 2009. The national strategy considers a number of areas including:

- Measuring, understanding and reporting needs of autistic people
- Workforce development
- Health, care and wellbeing
- Specific support
- Participation in local community

In addition, there are a number of national initiatives aiming to improve the experiences of autistic people living in the United Kingdom. These include:

- The Government's [Think Autism Strategy Governance](#) refresh
- [Transforming care](#)
- Public Health Outcomes Framework Profiles for:
 - [Learning disabilities](#)
 - [Young people's mental health](#)
- National Autistic Society's [Too Much Information](#) report
- [Disability Confident Employer scheme](#)
- Local Government Association's [So what, what next?](#) project
- Public Health England's [Autism Self-Assessment Framework](#) exercise

Local initiatives include:

- Nottingham City Councils Autism Strategic Framework (under development) 2018-2020
- [Nottingham and Nottinghamshire Sustainability and Transformation Plan](#) 2016-2021
- [Nottinghamshire Transforming Care Partnership](#)
- [Autism East Midlands](#) activities

4. Population groups

This section highlights that the needs of autistic people in Nottingham are diverse including physical and mental health conditions and social problems.

Figure 1 is a visualisation of the needs of autistic people and how they can be supported to fulfil their potential. It was created by Nottingham's Autism Strategy group to capture the spectrum of autism and how needs differ; the tiered nature is a rough approximation of the proportion of autistic people in each segment of the pyramid. The group recognise that the visualisation has limitations in describing the broad range of needs of people on the autistic spectrum.

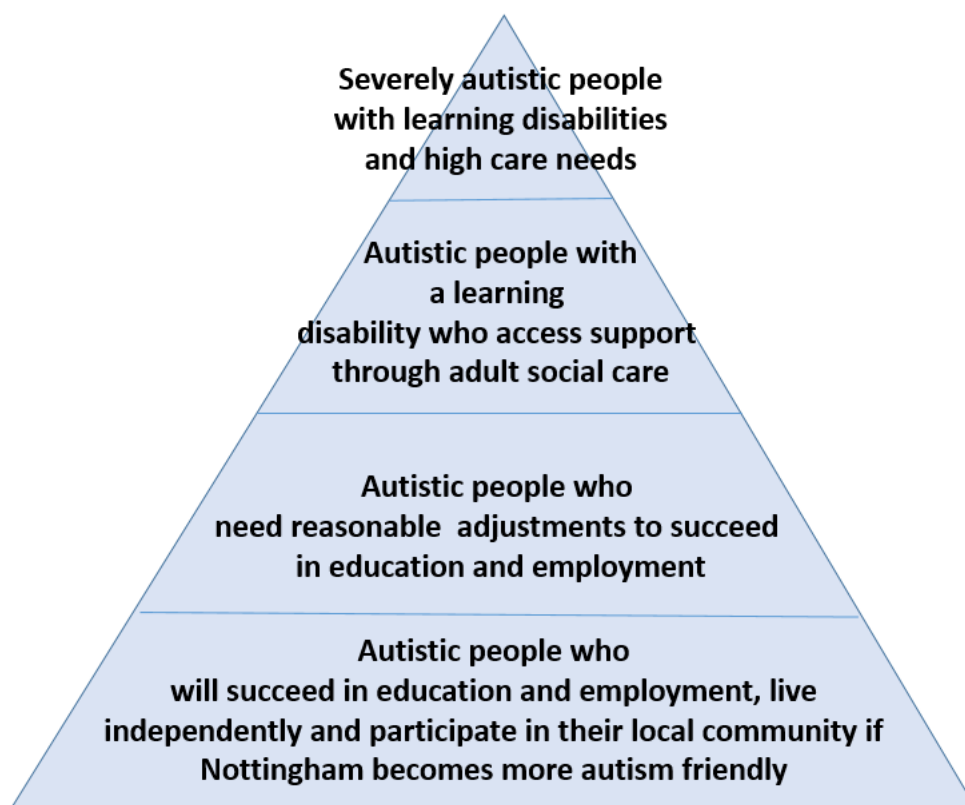


Figure 1: A visualisation of the differing needs of autistic people created by Nottingham's Autism Strategy group

Some of the key sub-groups are listed below, although we acknowledge this does not cover the full range of subgroups that exist within the city. A more detailed description of the research underpinning this section of the report can be found in Appendix B.

4.1 Autism in the general population

The latest [prevalence estimates](#) on autistic adults in England indicate that 1.1% of the population may be on the autism spectrum with incidence rates higher in men (2%) than women (0.3%).

4.2 Autism and learning disability

Autism is not a learning disability. The co-occurrence of autism alongside a learning disability is common in the United Kingdom. The [National Autistic Society](#) estimates that approximately 44% - 52% of autistic people may have a learning disability¹ and that 48% - 56% of autistic people do not have a learning disability.

¹ Defined as IQ<70.

According to [Autistica](#), around 4 in 10 autistic people have a learning disability. It is estimated that [between 31% and 35.4%](#) of people with a learning disability are also autistic.

4.2 Autism and physical health

The research overall has supported the notion that individuals with autism are exposed to the same health risk factors (e.g. obesity) as the general population but with additional autism specific factors (e.g. social impairment, repetitive behaviour). These factors and the co-occurrence of epilepsy and serious mental illness raise the index of suspicion that autistic people may face a poorer health outcomes and an increased mortality risk.

As a group, autistic people have a lower life expectancy than the general population. The UK's autism research charity [Autistica](#)'s [early death report](#) estimates (based partly on a study from [Sweden](#)) that in comparison to the general public people with an Autistic Spectrum Condition and no intellectual disability die an average of 12 years earlier (driven largely by suicide). Those with an Autistic Spectrum Condition and an intellectual disability die 30 years earlier (the leading cause being epilepsy).

Moreover, autistic people are exposed to the same health risk factors (e.g. obesity) as the general population but with additional autism specific factors (e.g. hyper/hypo sensitivity affecting food choices). For example, there is evidence to suggest that both autistic [children](#) and [adults](#) are at increased risk of obesity.

These factors and the co-occurrence of other chronic conditions raise the index of suspicion that autistic people face poorer health outcomes and an increased mortality risk. For example, Research has found that autistic [children](#) and [adults](#) are more likely to have a variety of chronic medical conditions including epilepsy, autoimmune endocrine disorders, gastrointestinal problems, type II diabetes and sleep disorders.

4.3 Autism and mental health

Autism is not a mental health problem. Mental health conditions such as anxiety, depression and obsessive compulsive disorder can be [more common amongst autistic people](#) in comparison to the general population. [Autistica](#) estimate that over 70% of autistic people have had a mental health problem. Additionally, [research](#) found that amongst autistic children aged 10-14, 71% experienced one and 41% experienced two more mental health problems.

Moreover, there is [research to suggest](#) an overlap between autistic spectrum conditions and borderline personality disorder and [higher rates of suicidal thoughts](#) amongst children and adults with autism in comparison to the general population. As mentioned above, [Autistica's report](#) states that the premature death of autistic people who do not have an intellectual disability is largely driven by suicide.

4.4 Autism and looked after children

Current studies demonstrating a link between children in care and ASD are sparse. However, recent investigations have prompted concerns that there is an [under-diagnosis of autism amongst children in care](#). Research has also found a [higher prevalence of autism amongst adopted children](#) in comparison to the general population. A [UK survey](#) of over 1,000 children in local authority care found a higher prevalence of caregiver-reported autistic traits than would be expected in the general population.

Moreover, [research](#) indicates similar presentations of attachment disorders and Autistic Spectrum Conditions, which may conflate issues and could lead to misdiagnosis of autism.

4.5 Autism and attention deficit hyperactivity disorder

Autistic people may also have [Attention Deficit Hyperactivity Disorder](#) (ADHD). Research suggests that ADHD is amongst the most common conditions to co-occur with Autistic Spectrum Conditions in [adults](#) and [children](#). The co-occurrence of both Autism Spectrum Conditions and ADHD may be as high as [43%](#). However, prevalence estimates are unreliable due to very small number of prevalence studies looking at co-occurring ADHD and Autistic Spectrum Disorder and issues regarding undiagnosed or misdiagnosed Autistic Spectrum Disorder amongst people with ADHD and vice versa.

Locally, 21% of individuals accessing the Nottingham Asperger's Service that had both Asperger's Syndrome and ADHD.

4.6 Autism and substance misuse and homelessness

The evidence base on the numbers of autistic people amongst the homeless and substance user populations is limited. There is some research to suggest that people with [Autistic Spectrum Conditions](#) or [Asperger's syndrome](#) are more likely to use drugs and/or alcohol problematically. [A review of research studies](#) focusing on this topic noted that very little research had addressed the likely causes and frequency of substance misuse amongst autistic people. The authors also noted a lack of evidence on what interventions may be effective for this group.

There is some evidence to suggest a significant number of autistic adults are homeless. A [Shelter report](#) on autistic people who are homeless in Wales cites a survey by the National Autistic Society Cymru (2011) reporting that 12% of their adult participants disclosed being homeless at some point in their lives.

[Screening results](#) from a caseload (n=106) of a UK homeless outreach team indicated that 12.3% of homeless people had a range of autistic traits in line with diagnostic criteria, considerably higher than the estimated general population prevalence of 1%.

4.7 Autism and the criminal justice system

[A review of evidence](#) identified that people diagnosed with Autistic Spectrum Conditions are not overrepresented in the criminal justice system. [Another review](#), suggested the opposite. The authors found that the numbers of autistic people in the prison population may be higher than that of the general population and that there is potentially an over-representation of autistic people within the criminal justice system but that there is commonly an under diagnosis amongst offenders.

[A review](#) focusing of people with Asperger's syndrome indicates that they may be overrepresented in the criminal justice system when compared to the general population. The authors are careful not to link the condition to criminality but instead question whether people with Asperger's syndrome are, for a number of reasons, more vulnerable to breaking the law.

However, all of these reviews noted that the quality of existing research evidence is poor and therefore interpretation of the results should be cautious.

5. Prevalence estimates

Autism spectrum condition is lifelong, impacting on all aspects of the lives of the individual and their family. Whilst early detection of autism spectrum conditions has increased, for many there remains diagnostic uncertainty in childhood or no awareness until adulthood. Identification and diagnostic assessment of autism was identified as key priority by NICE (CG142, 2012).

Due to the problems in accessing data in respect of the actual number of autistic people in Nottingham, the best available national prevalence estimates have been applied to local demographic data.

5.1 Adults

Using [2016 mid-year population estimates](#) for Nottingham City and the prevalence estimates of adults with Autism in England, calculated by [Brugha et al \(2012\)](#), suggests that amongst those aged 18 or over there are 2,840 (1.1%) autistic people over the age of 18 in Nottingham City, 2% (2,600) of these are men and 0.3% (240) are women.

Due to the association between [Autistic Spectrum Conditions and Learning Disabilities](#) and the [reduced life expectancy of people with Learning Disabilities](#), areas with younger demographic profiles would be expected to have an increased number of adults with Autistic Spectrum Conditions and Learning Disabilities.

Data from the Nottingham City Asperger's Service indicates that between April 2017 and December 2018, 289 adults were assessed for an Autism Spectrum Disorder and approximately 65% (188 adults) were diagnosed with the condition.

5.2 Children

Using [2016 mid-year population estimates](#) for Nottingham City and the prevalence estimates of children with Autism in England, calculated by [Taylor et al \(2013\)](#) for the period 2004 to 2010, suggests that for those aged 17 or under there are 1,310 (3.8%) boys and 261 (0.8%) girls.

Annual incidence estimates were also calculated and indicate that each year 1.2/1000 boys and 0.2/1000 girls will be newly diagnosed with autism. This rate remained steady between 2004 and 2010, equating to 41 boys and 7 girls.

Paediatricians practicing in Nottingham can provide local information on the diagnosis rates of children with autism in the city. Figures for the period 2016-17 show that 500 children were diagnosed with Autistic Spectrum Conditions across Nottingham City and Nottinghamshire County.

There is a lack of local level data on the prevalence of Autistic Spectrum Conditions by age band. However, it is likely that there will be a higher number of diagnosed autistic people in younger age groups due to an increase awareness of the condition and higher levels of contact with statutory services (e.g. health care and schools).

6. The needs of autistic people

6.1 Gender

The experiences of autistic women and girls are still very much misunderstood. Whilst it is still more common for men and boys to receive a diagnosis of autism, there is increasing awareness that autistic women and girls may be better at masking their difficulties, leading to their autism being missed.

There is a higher proportion of males diagnosed with autism in comparison to females. The difference in proportions varies across studies with an average of [4:1](#) for autism spectrum disorder overall. However, [a recent review](#) of research approximates that this ratio is closer to 3:1. Moreover, [a 2013 review](#) of research indicates that this proportion may differ across the spectrum; towards the lower functioning end of the spectrum, the ratio has been estimated to be 2:1, whereas at the higher functioning end the ratio is approximately 6:1. Both reviews suggest that there is currently a bias in diagnosis of autism spectrum disorder towards males and that females at the higher functioning end of the spectrum are being under or misdiagnosed.

Scholars focusing on the [experiences of girls and young women](#) with Autistic Spectrum Conditions note that they use a variety of masking and imitation strategies to hide the day-to-day social challenges they face. [First person accounts](#) by two women with an Autistic Spectrum Condition that highlight these challenges have been published by the National Autistic Society. More information on the links between gender and autism can be found [here](#).

Locally, almost a third of individuals seeking a diagnosis and/or ongoing support from the Nottingham Asperger's Service in 2016-17 were women (n=109, 31%).

6.2 Ethnicity

There is currently a lack of data to determine with any confidence whether there are differences in prevalence between different ethnic groups in Nottingham. A recent [UK based study](#) suggests that children of Black and Minority Ethnic (BAME) group mothers were less likely to have a diagnosis of autism. For example, children from a Pakistani background were 70% less likely to have a recorded diagnosis of autism in comparison to children from a White British background.

The National Autistic Society have produced [a detailed report](#) on autistic people from BAME group communities. In brief, the report suggests that autistic people from these communities are less likely to be diagnosed, receive the benefits to which they are entitled and have access the appropriate services. This is considered to be due to a lack of awareness of autistic spectrum conditions in these communities, as well as a lack of knowledge amongst BAME groups of the rights and relevant services available to people with autism.

6.3 Socio-economic position

[A review of research studies](#), identified lower rates of autism awareness and diagnosis amongst children living in more deprived areas. [Research](#) conducted in the United Kingdom, using data from individuals in Bradford, suggests a significant under diagnosis of Autistic Spectrum Conditions for children of lower education status mothers.

6.4 Education

Many schools are very aware that children who have particular difficulties in learning require adapted learning strategies. Every term they report to the Department for Education about all children who have special educational needs and disabilities.

The prevalence of autism spectrum disorder amongst children from state funded school primary, secondary and special schools in Nottingham city was determined using Special Educational Needs data.

[This data is from 2018](#) and shows the number of children in every thousand who are recognised as having autistic spectrum disorders (i.e. combination of difficulties with verbal communication, interacting with other children or adults), not all will have been formally assessed.

As shown in Figure 2, the prevalence in Nottingham is 22% (95% confidence interval 20.7%-23.4%), this equates to 1,069 children. This proportion is higher than all other eight regions in the East Midlands (Nottinghamshire=16%; Lincolnshire=16%; Derby=16%;

Derbyshire=14%; Northamptonshire=12%; Leicestershire= 9%; Leicester=8%; Rutland=5%). This proportion is also higher than the regional (14%) and national (14%) average.

Area	Value	Lower CI	Upper CI
England	13.7	13.7	13.8
East Midlands region	13.7	13.4	14.0
Nottingham	22.0	20.7	23.4
Nottinghamshire	16.1	15.4	16.8
Derby	15.7	14.6	16.9
Lincolnshire	15.5	14.8	16.2
Derbyshire	14.4	13.8	15.2
Northamptonshire	12.4	11.8	13.0
Leicestershire	8.8	8.2	9.3
Leicester	8.2	7.5	9.0
Rutland	5.3	3.9	7.2

Source: Department for Education statistical collections: Special Educational Needs, local authority tables
<https://www.gov.uk/government/collections/statistics-special-educational-needs-sen>

Figure 2: Prevalence of autism spectrum disorder amongst children from state funded school primary, secondary and special schools in Nottingham city, 2018

Figure 3 shows a statistically significant rise in the number of autistic children known to Nottingham schools, increasing from 18.1% (828 children) in 2015 to 22% (1,069 children) in 2018.

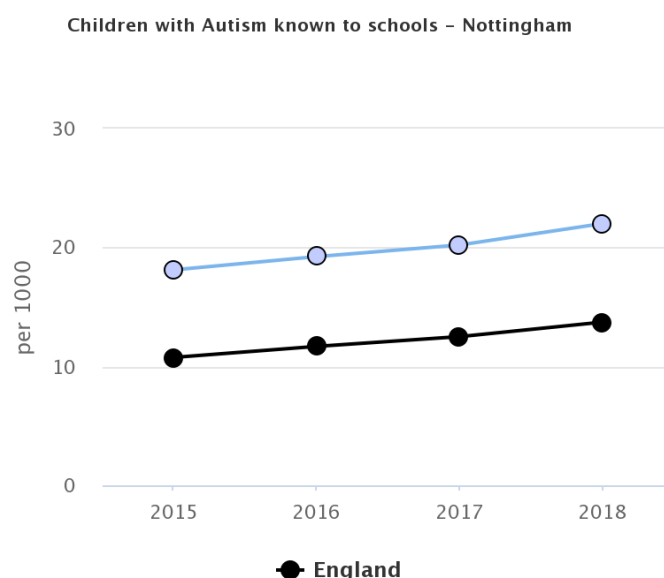


Figure 3: The number of children with autism known to schools in Nottingham city, 2015-2018

Local level data for 2017-18 held by the Autism team in the Inclusive Education Service at Nottingham City Council shows that for the period September 2017-March 2018 there were 980 children with autism known to schools. Of these, 307 (31%) receive High Level Need (HLN) funding and 233 (24%) have an Education, Health and Care (EHC) plan. It should be noted that these figures are taken from teachers in schools and therefore cannot provide a full picture of need in the city.

Approximately 27% of these children do not have a formal diagnosis of autism. However, information is obtained from teachers who may be under-reporting the number of children diagnosed and should therefore be interpreted with caution.

Moreover, whilst the Autism team do not generally work with children who do not have a diagnosis, some staff will pick up more children who do not have a diagnosis if they have extra capacity. In addition, some children are without a diagnosis because parents do not want a diagnosis and others are pending a diagnosis. Some early years (i.e. birth to 5 years) children are without a diagnosis and schools seek the Autism team's expertise for these children because they have speech and language difficulties.

Amongst the 374 children (10-17 year olds) in contact with Nottingham City Council Youth Offending Team as of May 2018, 94 have a diagnosis of Autism Spectrum Disorder and a further 6 shows signs of being on the spectrum but do not have a diagnosis.

6.5 Health

Data held by Nottingham City Council as of May 2018, shows that amongst the 4,966 children and young people (0-17 year olds) who are recipients of social care, 393 are showing signs of autism.

As of April 2018, amongst the 5,426 adult recipients of social care there were 72 people with Asperger's Syndrome or High Functioning Autism, 125 autistic people (excluding Asperger's Syndrome / High Functioning Autism) and 1 person with both.

In relation to primary care, the GP Learning Disability Register only captures autistic people who also have a Learning Disability. Currently, there are no specific primary care codes for autistic people and commonly allocated a code relating to mental health. Sometimes clinicians will document a diagnosis of Autistic Spectrum Conditions on the GP Learning Disability Register as an additional diagnosis, but not always. The primary care liaison team recognise the lack of data on autistic people as an issue.

Data from the Nottingham City Asperger's Service shows the growing population of people referred with signs of Asperger's Syndrome in Nottingham. For the period April 2017 and December 2018 the total number of adult referrals was 407, which has increased year on year since the inception of the service in 2009 (see Table 1). On average, 76% of these referrals are offered a diagnostic assessment and 65% of people assessed receive a diagnosis of autism.

The caseload of the Asperger's Service as of June 2017 was 439 people, 21% of those are considered to have combined Asperger's Syndrome and ADHD.

Year	Total Referrals	Diagnostic assessment
2009-10	116	74
2010-11	130	95
2011-12	147	108
2012-13	177	137
2013-14	181	117
2014-15	250	172
2015-16	251	177
2016-17	353	268
2017-18	407	289

Table 2: Nottingham City Asperger's Service number of referrals and assessments

6.6 Employment

There is a lack of local level data on the employment rates of autistic people in Nottingham. Using 2016 mid-year population estimates for Nottingham City and information from the National Autistic Society report [on the autism employment gap](#), which provides the proportions of autistic people in paid work, we can assume that there are 227,108 adults of working age in Nottingham and that 1 in 100 of them (2,271 people) will have autism.

National statistics suggest that 32% of autistic people are in some kind of paid work, of which 16% are employed full-time, equating to approximately 727 and 363 people in Nottingham respectively. This leaves an estimated 1,544 unemployed autistic people in the city.

Local data from the Nottingham City Asperger's Service show that, as of July 2018, 18% of the people currently accessing the service are in employment (63 out of 351).

The National Autistic Society also suggest that only 10% of autistic people receive employment support (approximately 154 people in Nottingham), although closer to 53% would like to receive it (approximately 818 people in Nottingham).

Nottingham Futures maintains a database providing information to the government on Nottingham City's 16-18 year olds who are Not in Employment, Education or Training (NEET). The below table provides a summary of these statistics for the last three years and shows the consistently higher proportion of young autistic people amongst those NEET in comparison to those in EET (Employment, Education or Training).

	Not in Employment, Education or Training		In Employment, Education or Training	
	Total (100%)	Numbers with Autistic Spectrum Conditions	Total (100%)	Numbers with Autistic Spectrum Conditions
2016	992	33 (3%)	7857	115 (1%)
2017	708	63 (9%)	7724	113 (1%)
2018	772	28 (4%)	7862	103 (1%)

Table 3: Nottingham Futures data (2016-2018)

DWP have noted that Autistic people are often in the wrong Employment and Support Allowance group and their potential to contribute to society hindered as a result. For example, some individuals allocated to the ESA support group (i.e. deemed unable to work) should be in either:

- The work-related activity group i.e. seen as able to work in the future and have contact with DWP every few months for support.
- The Job Seekers Allowance group i.e. actively seeking work with frequent review meetings and help from DWP)

DWP also identify a need for employers in Nottingham to be autism aware, confident and flexible. They should be encouraged and incentivised to employ people with autism.

6.7 Community presence

Community presence, in the context of this needs assessment, is about recognising the right of autistic people to fully participate in the community they live in including education, employment, volunteering and social opportunities. It recognises that some autistic people will need to make gradual steps towards employment. For example, an autistic person who feels unable to leave home and is socially isolated could be supported to attend a meeting in a local library; a seemingly small but significant step in community presence.

Nationally, there is a need to provide better environments for autistic people can fully participate in society. [Research suggests](#) that currently autistic people value environments that provide security and enable them to connect with others in their community and reduce feelings of isolation. There is also [evidence](#) that autistic students are at increased risk of physical, verbal and social victimisation than students without autism.

Nottingham is committed to becoming an autism friendly city where autistic people can feel part of and meaningfully contribute to their communities. As part of this initiative Nottingham City Council have been running autism awareness training sessions for both people within the council and external stakeholders (including Nottinghamshire Police, Department of Work and Pensions and Nottingham City Homes) to attend. The council has also developed an online e-learning course for its staff.

Local data shows that for the period March 2016 to December 2018, 16 autism sessions were delivered with a total of 215 people in attendance. The sessions have received positive feedback from participants with the majority reporting that attending the sessions increased their knowledge (78%), skills (65%) and confidence (73%).

Moreover, a total of 474 Nottingham City Council colleagues have completed the Autism Awareness e-learning course since 2016. Nottinghamshire Healthcare NHS Foundation Trust also offer their staff an Autism Awareness e-learning course. For the period November 2015 – November 2018 553 people have accessed this online training.

6.8 Housing

Not all autistic people have needs that require help with housing. However, many autistic people require accommodation support and adaptations in order to live independently. There are an increasing number of [housing options](#) for autistic people including supported living, residential care, living with family or independently with a care package in place.

At the same time, nationally [there is still a need for the upscaling of housing](#) initiatives and new models of care developed for autistic people, particularly those with complex needs (e.g. learning disability, mental health problem).

Locally, there appears to be a lack of data on the housing needs of autistic people and the number of autistic people who are also homeless.

7. National guidance and examples of Best practice

The [National Institute for Health and Care Excellence](#) (NICE) published its guidance on diagnosis and management of autism in the [under-19s](#) in 2011 and 2013 and in [adults](#) in 2012 with partial updates in 2016 and 2017. The guidance outlined the best ways to deliver and facilitate access to interventions and services for autistic children, young people and adults.

The **meaningful involvement of autistic people** and those who support them is a crucial when developing, implementing and evaluating initiatives to address the needs of this population. NHS England employ autistic people to assess NHS services and suggest improvements. The organisation has recently developed a number [quality checker tools](#) to support them to do this in a more systematic way.

[The Roche company](#) included autistic people as partners in their [clinical research trial development](#), providing expert and practical advice on the development, delivery and dissemination of the research.

Moreover, shifts in the perceptions of the public of Autistic Spectrum Conditions will facilitate their inclusion and allow them to become more independent. The Economic and Social Research Council have funded [research](#), co-produced with people who are on the autistic spectrum, to improve public understanding of autism in the United Kingdom. A surprising finding from the research was that:

“...even close family can misunderstand their autistic family member, sometimes failing to question their own assumptions about what he or she is thinking, and overgeneralising the extent of their social impairment”
([Improving public understanding of autism, 2018](#)).

[The Right Click Parenting Programme](#), a telehealth training programme for parents of autistic children, is a promising approach to support and educate parents who have children with the condition.

This misunderstanding of autistic people extends to healthcare professionals, who have recognised and are campaigning to [stop the overmedication](#) of autistic people and/or a learning disability in the United Kingdom.

The creation of **supportive environments** in which to maximise the life chances of autistic people through development and learning, improvements in social skills and communication, reduced comorbidity and disability, and provision of support to families and carers is a sustained theme running throughout the [research literature](#).

NICE showcase the [EdufitUK programme](#) as an example of best practice. The programme takes a holistic approach to the personal development of children and young autistic people as they transition into adulthood.

[Nottinghamshire iWork programme](#) offers support to people with a learning disability and/or Asperger's/Autistic Spectrum Condition in the county. There is no such provision available to citizens in Nottingham city.

[Towards work](#) is available to autistic people in Nottingham city, offering bespoke, personalised and tailored solutions to support the individual's journey towards personal progression and employment.

[Disability Confident Employer scheme](#) operates in Nottingham city which provides local employers with guidance and resources about employing autistic people.

7.1 Improving health outcomes of autistic people and multiple complex needs

[NICE guideline 142](#) for adults, recommends that all NHS staff should receive autism awareness training, with specialist training provided for staff in roles that have a direct impact on adults with autism. The guideline also recommended that care should be person-centred and recognise the individual needs of the adult with autism. All individuals involved in primary care need to ask themselves how easy it is for an adult with autism to access services and how well equipped is the practice to deliver effective care.

[NICE guideline 170](#) for children and young people includes the development of multidisciplinary teams and a focus on therapist-driven and parent-mediated interventions designed to ameliorate the core features of autism. Social support for the child or young person and his or her parents/carers as well as a smooth transition to adult services were noted. Recent [Scottish guidelines](#) reflect a growing body of evidence that Autistic Spectrum Conditions can affect either gender at any age; and thus highlights the need for prompt

diagnosis and appropriate intervention, specialised educational programmes, and structured support to help autistic people across the whole age range to maximise his or her potential.

A [Nottinghamshire based information programme](#) providing reliable and timely information on autism for patients, parents and carers to inform and empower them about medical conditions, treatments and services to support self-care, has been highlighted by NICE as an example of best practice.

The University of Bristol [Learning Disabilities Mortality Review](#) (LeDeR) makes recommendations in order to meet the needs of autistic people who have multiple complex needs:

“Current NHS England recommendations are that commissioners should extend the offer of a named local care coordinator to all people with learning disabilities and/or autism who have a mental health condition or behaviour that challenges (LGA, ADASS, NHSE, 2015; Public Health England, 2017). In the light of the extent to which potentially avoidable contributory factors leading to death are related to poor inter-agency collaboration and communication, we do not believe that this is sufficient. Rather, we suggest that parity is upheld between the impact of physical and mental health conditions, and that any person with learning disabilities with two or more long-term conditions, of whatever nature, is supported in managing their overall healthcare needs with a local, named health care coordinator.” ([LeDeR key messages for mortality collaborative, 2017](#)).

[The Mitford unit](#), at Northgate Hospital in Northumberland, is a CCG commissioned service for autistic people who have complex needs which cannot be met by local assessment and treatment services. The service also provides diversion for individuals who have been inappropriately placed within secure services. The unit has been specifically designed to allow for highly individual environmental adaptations to reduce anxiety and positively impact on challenging behaviours. Its success is due to its person-centred design and highly trained staff.

7.2 Housing for autistic people

[The Kingwood Trust](#) have written a report with recommendations and examples of best practice on [community housing designs](#) for autistic adults.

[The Portobello Street project](#) operating in Hull and run by [the Home Group](#) is an excellent example of how a service can improve the home environment of autistic people, offering:

- The right support in the right place
- Psychologically Informed Environments
- Positive behaviour support
- Reablement focus
- Providing the property solution
- Family involvement
- Physical health support

8. Current provision for autistic people in Nottingham City

The provision of services that can meet the needs of autistic people in Nottingham City are varied. Services include those that are specifically for autistic children and adults as well as mainstream services (e.g. primary, secondary, tertiary NHS services and voluntary sector organisations) that are available to all citizens in Nottingham.

8.1 Children

[The Autism team](#) in the Inclusive Education Service based at Nottingham City Council offer 1:1 support for children with autism in school and college as well as their transitions between primary, secondary and college. The team also provide a variety of autism awareness training sessions for staff in schools:

- An introduction to autism (60 minutes training)
- Making sense of autism (90 minutes training)
- Good autism practice (whole day training)
- Leading good autism practice (whole day training)

To date, the Autism team at Nottingham City Council have delivered training on autistic spectrum disorder in 103 out of 122 state funded schools across the city.

Autistic Spectrum Condition [diagnosis and assessment for children](#) in the city is available via specialist paediatricians employed by Nottinghamshire Healthcare NHS Trust.

Paediatricians and the Nottingham City Council Autism team are developing a communication pathway whereby clinicians who diagnose children in the city with autism will come to the attention of the Autism team who can provide ongoing support for the child whilst they are in school and college. Moreover, Nottingham City Council have commissioned the recruitment of an additional Clinical Psychologist and Educational Psychologist in 2018 to assist with diagnosis and formulation of autism in children and ensure that the diagnosis of autistic children meets [NICE guidelines](#).

[Pathological Demand Avoidance](#) (PDA) is increasingly recognised as one of the profiles present in some individuals on the Autistic Spectrum Conditions. [The Elizabeth Newson Centre](#) in Nottingham is one of only a handful of services in the United Kingdom that provides PDA diagnosis and support.

8.2 Adults

The Nottinghamshire Healthcare NHS Trust [Nottingham City Asperger Service \(NCAS\)](#) is a multidisciplinary diagnostic assessment and short-term support service for adults with Asperger syndrome living in Nottingham city. The service starts by identifying the person's needs (e.g. formal diagnosis, areas of particular concern, social inclusion), followed by a structured assessment. This is often seen as a starting point for understanding individual difference, and receiving appropriate specialist support.

Following the initial assessment, different types of interventions are considered. Where needed, the service works closely with allied agencies such as adult mental health, substance misuse, social care and forensic services.

Referrals to the Asperger's service have increased year on year and the capacity of the service is struggling to meet this growing demand. Current waiting times and provision are:

- 8 week wait for the first appointment.
- 20 week wait for diagnostic assessment.
- 6-12 sessions of support.

Other Nottinghamshire Healthcare NHS Trust services offering specialist support to autistic people are the Community Forensic Intellectual Developmental Disability team, Liaison and Diversion Service and the Adults with ADHD service.

[Community Forensic Intellectual Developmental Disability team \(CFIDD\)](#) service that supports adults with a learning disability and or autism who are at risk of being involved with the criminal justice system, across Nottinghamshire (both City and County). The multi-disciplinary team offer inpatient and community services as well as speech and language therapy.

[Liaison and Diversion Service](#) operates in custody suits and courts. They offer assessment, liaison, diversion and when required short term assertive follow up to vulnerable individuals (including autistic people) at the earliest point of the criminal justice service.

[Adults with ADHD service](#) offers diagnostic assessment, consultation regarding treatment options, and short term psychological support. The service can be accessed via secondary mental health care services. The Adult ADHD clinic at QMC, Nottingham is a small specialist tertiary service established in 2009. The clinic is internally funded by Nottinghamshire Healthcare NHS Trust to facilitate implementation of the NICE ADHD assessment and treatment guidelines. There is no externally commissioned service provision for adults with ADHD in Nottinghamshire. The clinic operates two-days per calendar month and offers specialist diagnostic assessments, second opinion assessments, treatment consultation and short-term psychological intervention. The clinic liaises with adult mental health services who also support adults with/suspected of having ADHD. The clinic also co-delivers the 'Living Well with Adult ADHD' course at Nottingham Recovery College, runs training workshops for clinicians, and participates in research.

NHS Nottingham City CCG commission an [acute learning disability liaison service](#). The team have identified that there is growing need to support autistic people. Moreover, the [Community Intellectual Learning Disability Nursing Team \(CLDT\)](#) offers support to autistic people who also have a diagnosed intellectual disability in the city.

Specialists working in Nottinghamshire Healthcare NHS Trust have identified a gap in knowledge of Autistic Spectrum Conditions amongst healthcare professionals. Notably, the City Primary Care Health Facilitators, commissioned by NHS Nottingham City Clinical Commissioning Group (CCG) provide autism awareness training across the health community and assist services to make Reasonable adjustments. The [Nottingham City Asperger Service \(NCAS\)](#) also provides training to staff and care teams in order to raise awareness of autism spectrum conditions and facilitate the support other teams provide.

However, training needs to be increased and delivered across all health, social care and emergency services operating in Nottingham. Currently, autism awareness remains low in the city and reasonable adjustments are not commonly applied.

Specialists working in Nottinghamshire Healthcare NHS Trust have also identified a lack of primary care provision for autistic people and a lack of post diagnosis support for autistic people and their families, including person-centred holistic support packages, access to clinical psychology, talking therapies and good quality education information. Currently, a diagnosis of autism is considered the endpoint. However, for most individuals this is often just the beginning.

[The Metropolitan Housing Association](#) provide up to 15 months holistic support to autistic people in Nottingham. They offer help with a range of issues including help with housing, independent living skills, benefits advice, access to healthcare and education, training and employment support. The service is available to people with Autism or Asperger's who are aged over 16 years old, live in Nottingham City and would benefit from support to enable them to live independently.

The [Work and health programme](#) is available through Nottingham City Council Department of Work and Pensions to autistic people who are seeking extra support to gain either paid or unpaid work.

[Working links](#) and [Towards work](#) are based in Nottingham and support people with a range of needs including autistic people. [Working links](#) offer a comprehensive assessment with an occupational therapist and develop a package of support to help the person meet their goals and aspirations. [Towards work](#) provide support to autistic people, helping them to find personalised and tailored solutions to support their journey towards personal progression and employment.

[Nottingham Futures](#) also operate in Nottingham and support young people with or without autism to access further education, training and employment.

Employment advisors are now available in primary and secondary healthcare services. For example, employment workers are based in:

- [Improving Access to Psychological Therapies](#)
- Some GP surgeries
- [Insight healthcare](#)
- [Individual Placement Support](#) (Nottinghamshire Healthcare NHS Trust)

[Autistic Nottingham](#) is an organisation ran for and by Autistic adults who do not have learning disabilities (such as Asperger's Syndrome). They offer an increasing number of services such as advocacy, an employment forum, workshops and a monthly social event.

[Autism East Midlands](#) is a non-profit organisation who also have a range of services for autistic adults in Nottingham. Employment support workers are available who can help autistic people apply for employment reasonable adjustments and the access to work scheme.

Organisations who operate in Nottingham and are committed to improving the inclusion of autistic people in their local communities include the [East Midlands National Autistic Society](#).

Work being led by the Nottingham City Council Autism Strategy (2018-2022) group, including:

- The expansion of autism awareness training [Nottingham City Council autism awareness](#) and Autism Champions recruitment.
- Improve existing and influence new environments in Nottingham to be autism friendly.
- Better access to public transport for autistic people.

9. Local views

Discussions with autistic people and their carers in Nottingham City, via focus groups and 1:1 meetings, have reported a number of challenges affecting them and members of the public. These include:

Difficulties in accessing healthcare services.

There is a lack of understanding of autism amongst healthcare professionals. It is often assumed to be a learning disability and there is general confusion over the needs of autistic people. Autistic traits that are not stereotypical are often missed and reasonable adjustments are not put in place.

There is difficulty in communicating effectively with all partners who support autistic people (e.g. sending letters to carers regarding an autistic person's appointment or arranging for consent to share autistic person's information with carers and/or other organisations who support them).

Post diagnosis support has been reduced. Past provision of 8 weeks of counselling and wrap around support addressing a wide range of needs appears to be no longer available to autistic people.

Difficulties in obtaining autism diagnosis in primary care at all stages in a person's life due to concerns by professionals of labelling or because they do not see it as important or due to the fact that there is no specific treatment.

Autistic people often dislike the 'high functioning' diagnostic label but feel those with less obvious autistic traits are forced to 'put it on' to get the support they require.

Poor access to appropriate mental health services such as Improving Access to Psychological Therapies (IAPT). Programmes tend to focus on Cognitive Behavioural Therapy (CBT) techniques which is not necessarily helpful when fixed autistic traits and modifiable behaviours are not differentiated from one another.

Autistic people from BME communities.

There appears to be a lack of understanding or 'blindness' amongst professionals to autistic traits in BME groups, dismissing them as cultural rather than autistic.

Workplace and educational settings.

"It's one thing that services and businesses don't know about autism but listen to us when we try help you understand."

Workplaces often do not make reasonable adjustments for their employees who have autism.

There is a general lack of understanding amongst colleagues who perceive the autistic person as being rude (despite no customer complaints being made). Autistic people are often not viewed as an asset to a team.

Language used in some workplaces makes it difficult for autistic people working there. For example, a well-known catering establishment has two types of bacon on their menu (breakfast meal and in their burgers). The establishment often uses the statement 'we're out of bacon' in the morning, which can be confusing for autistic staff who then tell all customers that there is no bacon available throughout the day.

There are examples where colleges and universities are not listening to adjustment requests of their autistic students. Colleges and universities often have stereotypical ideas of autism and do not acknowledge the wide variation amongst autistic people, leading to 'all or nothing' adjustments. For example, offering someone to read lecture slides for an autistic person (an adjustment commonly used for other disabilities) is not necessarily appropriate for autistic students because it is often not the reading but the language contained within the slides that can cause difficulties.

There are instances where nurseries/primary/secondary schools have not identified the autistic traits of their students leading to their behaviour being viewed as 'disruptive' and 'bad', at times leading to alternative provisions being put in place and/or exclusion.

Criminal justice system.

Cases have been highlighted where a lack of understanding of autism in the criminal justice system has led to the unnecessary suffering of autistic people detained in custody. For example, spending the night in a custody suite which is unfamiliar can lead to fear, anger and agitation which if not dealt with effectively can escalate and lead to further charges and labelling of the individual as 'bad'.

Poor adjustments made for autistic people navigating the social care and criminal justice system e.g. attending multi-disciplinary safeguarding meetings, which include a number of strangers asking questions can increase displays of agitation and aggression which would not have occurred if 1:1 meetings had taken place instead.

Community presence.

There is persistent negative causal language within society that, whilst not aimed at autistic people, is still offensive to them e.g. *'that's so....retarded, spastic'*.

The opportunities to socialise for young autistic adults is limited, particularly for those 'higher functioning'. There are few people in mainstream social and sports clubs who understand autism. This can lead to feelings of isolation and loneliness amongst autistic people.

Portrayal of autistic people in the media is often negative. For example, the English television quiz personality [Anne Hegerty](#) was one of the first examples of someone with autism who was intelligent and high functioning and who received a positive high profile.

Media programmes often portray the ‘unbelievable’ aspects of autism in programmes like [The Undateables](#) i.e. how can someone be autistic and good looking.

Community training that does not meaningfully involve autistic people isn’t always correct or effective and does not always portray autism very well. There are cases where training has been presented by people (including parents or carers of autistic people) who misunderstand or portray only one type of autism. The training often misses the autistic culture and group identity of autistic people when courses are run by people who aren’t autistic.

Support for the carers of autistic people.

There is a lack of specialist placements/short breaks/day services for autistic people which not only benefit their wellbeing but also give carers some protected time to focus on their own needs.

Discussions with clinicians from [Nottinghamshire Healthcare Foundation Trust](#) have highlighted a number of issues facing autistic people in Nottingham.

Post-diagnostic support for autistic children and adults in Nottingham.

There is a perception that, currently, a diagnosis of autism is seen as the end point. However, for most individuals this is often the beginning of their journey. Increasing the capacity of the Asperger’s service for adults, who are experiencing increasing demand in the city, would be one way to achieve this.

Provision of services for autistic people and ADHD in the city.

Approximately 20% of autistic people seen by the Asperger’s service also have ADHD. However, there is currently no shared care protocol or pathway for prescribing.

Support for autistic people with restricted food disorders in the city.

The Asperger’s service have identified increasing numbers of autistic people who have a restricted food disorder and need more specialist support.

Discussions with representatives from Autism East Midlands have drawn attention to additional needs of autistic people in Nottingham.

Support for parents of autistic children and/or adults. Ensuring that those who love and care for autistic people are aware of the services at their disposal and have the ability to take a break and receive the support and rest they deserve.

Support for teenagers and young adults with Asperger's. Due to perceived lower levels of need they do not meet statutory service thresholds but are largely reliant on their families (i.e. socially isolated, not in education, employment or training). Improving the numbers of employers in Nottingham who are autism confident may be one way to achieve this aim.

Support for autistic parents. A diagnosis of autism does not stop someone from being a good parent. However, some specialist information, advice and support would be beneficial. Providing online and/or face to face support for autistic parents in Nottingham could be one way to achieve this aim.

Discussions with representatives from the Department of Work and Pensions (DWP) has identified the following issue facing autistic people in Nottingham.

Support for autistic people to access the correct benefits and, where possible, employment, education and training. Working with DWP to ensure that autistic people are in the correct Employment and Support Allowance group and in contact with the right services and offering, the [Nottinghamshire iWork programme](#) currently operating in the county to citizens in Nottingham city, could be two ways to achieve this aim.

Discussions with representatives from the Low Secure Community Forensics & Local Partnerships Speech and Language Therapy team have identified the need for:

Increased understanding and awareness of autism in adult mental health services.

The team have observed inappropriate mental health hospital admissions of autistic people. A patient's presentations is sometimes incorrectly identified as being due to an acute mental health need when in fact their presentation is likely to be related to their autism.

In other cases, autistic people who do have mental health needs do not receive reasonable adjustments and mental health staff understanding of autism is not adequate. This can result in diagnostic overshadowing (with the focus being on mental health diagnoses rather than autism). It can also negatively affect autistic people's access to verbally mediated treatments and involvement in care planning.

Discussions with representatives from Nottingham City POhWER have elucidated the following need.

- Systems that allow autistic people to return to the community quickly after a hospital admission (e.g. more community placements).
- Skilled, knowledgeable, confident, trained support staff who can work in an appropriate environment to meet the needs of people with autism who have multiple complex needs.
- More bespoke packages of care that are tailored to the individual in order to prevent 'placement breakdowns'.

10. Unmet needs of autistic people in Nottingham City

This assessment demonstrates that the needs of people on the autism spectrum are as varied as they are. Some autistic people and have an associated learning disability are non-verbal and have a lifelong need for care whilst other autistic people are highly intelligent, analytical and creative. Everyone with autism benefits from the right support, delivered in the right way at the right time by the right people.

The needs of autistic people in Nottingham, identified through this assessment, are summarised here.

We need to generate evidence that can support local views. It is imperative that autistic people as well as those who care for them are empowered to highlight the issues that autistic people face in the city and that those responsible for meeting those needs implement strategies to generate additional evidence which can support issues raised by local stakeholders as well as monitor progress in tackling them. This can be achieved through ongoing and meaningful engagement with autistic people and those who care for them, improved data collection and research.

We need to collect more data. Current data collection and collation makes it challenging to state accurately the number of children, young people and adults with autism in Nottingham. Data collection on autism, including the number of people diagnosed with autism, is limited. Many services do not collect information on the number of autistic people they have contact with and as such it can be challenging to understand whether autistic people have equitable access to, and outcomes from, services.

Examples:

- Improve staff recording of autism in health fields of Nottingham City Council Adult Social Care dataset.
- The Employment, education, training needs of young autistic people.
- Housing needs of autistic people and the numbers who are homeless.
- Autistic people accessing primary care.

A [freedom on information request](#) from 2014 highlights how data held by the Department of Work and Pensions on employment related benefits and work programmes incorporates autistic people under the umbrella term “Pervasive Development Disorders”, used to cover Autism and related conditions such as Asperger’s Syndrome, Rett Syndrome and Heller’s Syndrome. More specific information on the employment rates and benefits claims of autistic people at a local and national level are required.

We need to improve the physical and mental health outcomes of people with autism.

This includes improving access to health services for co-occurring chronic mental health and physical health conditions, particularly amongst those with a learning disability, reducing levels of obesity and stopping the overmedication of autistic people, with or without a learning disability.

We need to improve awareness amongst health, social care and emergency service staff on the issues facing autistic people and referral pathways. Autism awareness training is being delivered by different specialist services. However, this training needs to be increased and delivered across all health, social care and emergency services operating in Nottingham. Currently, autism awareness remains low in the city and reasonable adjustments are not commonly applied.

We need to improve awareness, recognition and diagnosis of Autistic Spectrum Conditions amongst women and girls. In order to challenge the commonly held perception that “*women don’t have autism*” ([NAS, 2018](#)), by consulting and working with women who have autism in the city.

We need to improve awareness, recognition and diagnosis of Autistic Spectrum Conditions amongst Black and Minority Ethnic groups. To end the [stigma](#) surrounding autism found in some BME communities through education and engagement and by ensuring that services for autistic people are culturally competent.

We need to improve the awareness, recognition and diagnosis of Autistic Spectrum Conditions in more disadvantaged communities. Tackling the [lower rates of autism awareness and diagnosis](#) amongst children living in more deprived areas.

We need specialist placements/short breaks/day services for autistic people in the city. Ensuring that those who love and care for autistic people have the ability to take a break and receive the support and rest they deserve.

We need more housing options for autistic people in the city.

Following examples of good practice such as the [Home Group project](#) in Hull could be one way to achieve this aim. Other interventions included:

- Encouraging private landlords to complete autism awareness training and to become Autism Champions.
- Meaningfully involve autistic people to better understand what housing adaptations may support autistic people.
- Offer a broader range of supported living options.
- Housing and adult social care to work in partnership to support autistic people throughout their lives.

We need better joint working between Nottinghamshire Healthcare Foundation Trust and Adult Social Care services for people with autism.

This could be achieved through:

- The development of a joint strategy outlining the pathway to diagnosis and long-term support.
- Improved systems that allow people with autism to leave hospital as soon as they are ready and prevent hospital admission where possible.
- Recruitment of a specialist autism social worker.

We need meaningful involvement of autistic people in the planning and development of the services and facilities in the city.

Involvement of local peer led and non-profit organisations such as [Autistic Nottingham](#), [Autism East Midlands](#) and [National Autistic Society East Midlands](#) could be one way to achieve this aim.

We need more Autism champions in the city. Expanding current initiatives such as the [Nottingham City Council autism awareness programme](#) could be one way to achieve this aim.

We need to better understand and support autistic people who have multiple complex needs. Including those with a co-occurring learning disability, mental health and/or physical health condition, ADHD as well as those with social risk factors such as being in care, criminal justice system involvement, substance misuse, and homelessness. Developing person-centred holistic services and learning from best practice examples such as the [The Mitford unit](#) could be ways to achieve this aim.

11. Key References

1. Department of Health and Social Care (2018), *Think Autism strategy governance refresh*, [Accessed December 2018] available at: <https://www.gov.uk/government/publications/think-autism-strategy-governance-refresh-2018>
2. National Autistic Society (2016), *Too much information*, [Accessed October 2018] available at: <https://www.autism.org.uk/get-involved/tmi/about/report.aspx>
3. NHS England (2019), *Transforming care*, [Accessed January 2019] available at: <https://www.england.nhs.uk/learning-disabilities/care/>

Appendix A: What is a Health Needs Assessment?

[Health Needs Assessments](#) are an essential Public Health tools to enact change, informing commissioning and service planning. Health Needs Assessments are a systematic approach to identifying the health and healthcare needs of a population, and recommend changes to better match these needs, while ensuring that resources are utilised in the most efficient way.

The aim of this Health Needs Assessment is to:

- Describe the health and healthcare needs related to autistic people in Nottingham City.
- Review the evidence of best practice for meeting the needs of people with autism.
- Identify current service provision for autistic people in the city.
- Determine priorities for the most effective use of health resources to address gaps in service provision.
- Recommend changes to commissioning or provision of services.
- Feed into the autism strategy with will identify ways to make these changes happen.

Epidemiological Health Needs Assessment

This is an epidemiological Health Needs Assessment, concerned with a) the epidemiology of a condition or an issue of interest, b) with what current service delivery looks like and c) what the evidence base suggests is effective.

The epidemiological Health Needs Assessment utilises quantitative data drawn from both local and national sources, including the Special Educational Needs departments Nottingham City Council, adult social care services, and Nottinghamshire Healthcare Trust as well as national datasets and published research.

Issues relating to both the quality and availability of local data means it is difficult to determine prevalence of Autistic Spectrum Conditions and to capture the needs of autistic people in Nottingham City.

In terms of prevalence, services do not routinely collect data on the number of clients with autism and there are issues associated with the availability of data that cover all age groups and allows for comparisons with regional and national prevalence.

Autistic people accessing other services, such as mental health or learning disability services, may be subject to “diagnostic overshadowing” whereby they may be suspected of having an Autistic Spectrum Disorder not have not need diagnosed.

Some autistic people may have low levels of need and therefore not be accessing statutory services. It is therefore likely that this Health Needs Assessment is an under-representation of the number of autistic people living in the city and does not fully reflect the needs of those who do not access statutory services.

Information relating to diagnosis comes from the NHS service providers. Individuals diagnosed by private providers are not included in this data.

In order to circumvent some of these data limitations, the Health Needs Assessment has drawn up the best available research to identify prevalence estimates, which have been applied to the local population. However, this data should be interpreted with caution as most studies are based on child and adolescent client groups and conducted among white populations. It is unclear whether these prevalence estimates can be applied to an adult population and whether there are differences in prevalence between ethnic groups.

Appendix B: Literature review



Literature search
enquiry form.pdf



Autism HNA evidence
summary 1.pdf



Autism HNA best
practice.pdf