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Executive Summary

Introduction

Autism is "a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypical (rigid and repetitive) behaviours, resistance to change or restricted interests"[1]. The way that autism is expressed in individual people differs at different stages of life.

Adults with autism face many challenges. Often, they also have co-occurring conditions such as learning disabilities or mental health problems. Those who have higher functioning autism feel they have a 'hidden' condition which is not easily recognised or understood by professionals or the public.

This Joint Strategic Needs Assessment (JSNA) will use the term '**autism**' as an umbrella term for all such conditions, in line with the terminology adopted by key representative organisations such as the National Autistic Society. The chapter will focus on adults with autism however, as part of our understanding of the health and wellbeing needs of this group, the issues faced within childhood may be touched upon.

[1] National Institute for Health and Care Excellence (2012) "Autism spectrum disorder in adults: diagnosis and management", page 5

Diagnosis and prevalence

Adult Autistic Spectrum Disorder (ASD) is often under-diagnosed, under-reported and misdiagnosed[2], largely due to the social and communication difficulties listed above. As there is no definitive test for ASD, diagnosis is based on the range of features evaluated by a combination of specialists who work together to make an assessment.

It is estimated that around 700,000 people in the UK may be autistic, or more than 1 in 100 in the population. The Adult Psychiatric Morbidity Survey (APMS) (2014) found the overall prevalence of autism to be 0.7 %, and was higher in men (1.1%) than in women (0.2%).[3] In Nottinghamshire POPPI and PANSI estimates give figures of 5715 males and 667 females with autism (a combined total of 6382. Locally one of the key issues for adults with autism is that they risk falling into the gap between services for people with learning disability and services for people with mental health conditions if they have no diagnosed or recognised comorbidities so could struggle to receive the help they need.

Unmet need and gaps

As part of the Autism Self-Assessment Framework (SAF)[4] for Local Authorities, a number of actions have been identified which will significantly impact in a positive manner on the lives of people living with autism.

Table 1: Actions for Local Authorities identified from the Autism SAF

** Comments taken from the Autism Self-Assessment Framework are in italics*

Pathway step	Unmet need/service gap
Training for staff providing services to people with autism	*NCC training is monitored. Is NHS training monitored? Training for hospital staff is not mandatory.* *There is no co-ordinated system of evaluation around the effectiveness of training on practice.*
Identification and diagnosis of autism in children and adults leading to assessment of needs	*See NICE ASD Local care pathway* *Improved referral route – how do GPs record statistics?* *Introduce central system for recording diagnosis to better service the requirements of planning and commissioning services* *Different routes to diagnosis – introduce integrated pathway with separate routes for Learning Disability/non Learning Disability*

[2] Department of Health, Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, March 2015, page 34

[3] Brugha et al (2012) Estimating the Prevalence of Autism Spectrum Conditions in Adults : Data quality and methodology document , NHS Information Centre

[4] https://www.gov.uk/government/publications/autism-self-assessment-framework-exercise

Planning for transition services	More support needed for individuals, parents & carers when moving from Children's to Adult Services
Local provision of services for children and adults	*No psychology service in the County and there is limited availability of Speech and Language Therapy (SALT) and Occupational Therapy (OT) services* *Crisis services to meet needs of people with autism* *District Councils are currently assessing how they might meet autism needs in housing strategies with trained staff*
Reasonable adjustments and equality	*Meet needs of older people/women/BME e.g. bespoke training particularly around cultural and religious needs, accommodation needs for 65+, and potential increase in women presenting with autism.*
Supporting people with complex needs who may display challenging behaviour	The transforming Care Partnership Programme is currently addressing the needs of such people
Employment for adults with autism	*Build employer capacity and support people with Autism Spectrum Disorders, and their families* *Voluntary opportunities?*
Working with the Criminal Justice System	*Training for Custody Suite Officers and Probation Service – e-learning to be shared?*

Recommendations for consideration by commissioners

	Recommendation	Responsibility
Strategic		
1	Create a multi-agency task and finish group for autism as per the Statutory Guidance[5] with assistance from the Health and Wellbeing Board as representatives of key partner organisations (i.e. assistance with identifying and gaining commitment from various stakeholders). The group will ensure the facilitation of a co-ordinated response and enable learning from good practice already available in some areas. As such it will be responsible for writing a local Autism Strategy and developing and implementing an Autism Action Plan based on the findings of this JSNA and the Self Assessment Framework (SAF). The Action Plan will fulfil a SAF target for 2019. The Health and Wellbeing Board will approve the Strategy and Action Plan in line with the Nottinghamshire Health and Wellbeing Board Joint Health and Wellbeing Strategy 2018-2022 priorities for Healthy and Sustainable Places[6]. Responsibility for delivery against the Action Plan and Strategy will lie with the Mental Health, Autistic Spectrum Disorders and Learning Disabilities Integrated Steering Group	The Mental Health, Autistic Spectrum Disorders and Learning Disabilities Integrated Steering Group with approval from the Health and Wellbeing Board
Health and Wellbeing promotion		
2	Identify specific needs around protected characteristics particularly older people, people from minority ethnic and cultural groups and women, from diagnosis to services available to ensure equality of access. Further research will ensure that services are appropriate for these groups and facilitate their engagement	All public sector agencies alongside voluntary and community sectors
3	At transition stage, build employer capacity and support and resources for people with ASD and their families. Increase the ability of young people to gain the skills they might need to gain employment and reduce the costs of unemployment	Adult Social Care Department, Local Authority
4	Work with local businesses and organisations to maximise employment opportunities for people with autism (not just those at transition) to maximise economic and individual wellbeing across all ages.	Place Department, Local Authority working in partnership with D2N2
5	Build community capacity and community responsibility to support people with Autism. Look at modifications to existing services to make them more accessible	Local Authority

[5] Department of Health, Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, March 2015, page 30

[6] Nottinghamshire Health and Wellbeing Board Joint Health and Wellbeing Strategy 2018-2022, page 4

	Recommendation	Responsibility
Service Delivery		
6	Provision of appropriate training for staff and volunteers working both specifically and more generally with local people within Nottinghamshire. This will enable more systematic availability of services and knowledge of personnel within these services	Nottinghamshire County Council, NHS Commissioner and Provider agencies, voluntary and independent sectors
7	Monitor and evaluate training within all agencies including Experts by Experience training – to enable all agencies to understand how best they might meet the needs of autistic people, as well as knowledge around their own staff groups	Nottinghamshire County Council, NHS Commissioner and Providers agencies, voluntary and independent sectors
8	Investigate how diagnostics and the autism pathway could be improved (including post-diagnostic support). A formal pathway is currently not available and would greatly enhance the lives of those with autism particularly where early intervention services can be put in place	Clinical Commissioning Groups
9	Local audit of poor take-up of primary care services and overuse of acute services by those affected by autism.	NHS bodies and NHS Foundation Trusts
10	Address the medical and lifestyle issues which result in poorer health outcomes and increased mortality	NHS and Local Authority Commissioners
Data		
11	Set up and improve data collection across agencies around autism e.g. GPs. This will enable all agencies to gain a true picture of how services are operating and where gaps might exist	NHS Commissioner and Provider agencies and Nottinghamshire County Council

Nottinghamshire Health & Wellbeing Board

Full JSNA report

What do we know?

1. Who is at risk and why?

The exact cause of autism is still unknown, however research suggests that a combination of factors - genetic and environmental - may account for the difficulties experienced by people with autism in terms of social interaction and communication. There is strong evidence to suggest that autism can be caused by a variety of physical factors, all of which affect brain development. Autism is not caused by a person's upbringing or their social circumstances and is not the fault of the individual with the condition.[7]

See also Causes of autism

1.1 National picture

Details of the national picture given below are taken from the National Autistic Society website

It is estimated that approximately 1% of the population of the UK have autism, this equates to approximately 700,000 people[8]. The Adult Psychiatric Morbidity Survey (APMS) (2014) found the overall prevalence of autism to be 0.7 %, and was higher in men (1.1%) than in women (0.2%).[9]

Autism is a spectrum condition. All autistic people share certain difficulties with social interaction and communication, but being autistic will affect them in different ways. These differences, along with differences in diagnostic approach, have resulted in a variety of terms being used to categorise autistic people. Terms that have been used include autism, autism spectrum disorder (ASD), autism spectrum condition (ASC), atypical autism, classic autism, Kanner autism, pervasive developmental disorder (PDD), high-functioning autism (HFA), Asperger syndrome and pathological demand avoidance (PDA). Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. All people on the autistic spectrum can learn and develop and, with the right sort of support, all can be helped to live more fulfilling lives of their own choosing.

Because of recent and upcoming changes to the main diagnostic manual (DSM-5) regarding diagnostic terminology, 'autism spectrum disorder' (ASD) is now likely to become the most commonly given diagnostic term. However, clinicians will still often use the historic additional terms to help describe the particular autism profile presented by an individual.

Often, a child or young person displays behaviours that challenge (i.e. 'Behaviour can be described as challenging when it is of such an intensity, frequency, or duration as to threaten

[7] The National Autistic Society
[8] The National Autistic Society
[9] Brugha et al (2012) Estimating the Prevalence of Autism Spectrum Conditions in Adults : Data quality and methodology document , NHS Information Centre

the quality of life and/or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion.'[10]), but their learning disability, autism or mental health problems are not diagnosed (possibly masked by the multiple nature of the child/ family's difficulties). This can lead to being ineligible for support from a Community Learning Disability Team or social care services and accessing or maintaining mainstream school or services can be difficult due to these issues.

Adults with autism who display challenging behaviour can often be misunderstood. A diagnosis of autism and functional analysis of their behaviour is therefore essential to ensure that their behaviour is regarded as a form of communication. Trying to understand what need the challenging behaviour is meeting in the person's daily life means that the person can be helped to communicate in different ways.

The National Institute for Health & Care Excellence (NICE) Quality Standard QS51[11] provides guidance around Autism and has indicated that organisations should take a multi-agency approach to enable timely diagnosis. As a result, support, if required, can be put in place at the earliest opportunity. Guidance for under 19's was checked in relation to this quality standard in 2017. The source guidance on autism spectrum disorder in under 19s: recognition, referral and diagnosis has been updated but no changes to the quality standard were deemed to be needed. This should substantially reduce the number of people presenting as adults with Autism having not been diagnosed earlier.

The National Autistic Society state that getting a timely and thorough assessment and diagnosis may be helpful because:

- It helps autistic people (and their families, partners, employers, colleagues, teachers and friends) to understand why they may experience certain difficulties and what they can do about them

It allows people to access services and support.

1.2 Diagnosis

The Department of Health has said that many people with autism are likely to be undiagnosed or misdiagnosed. A Parliamentary Briefing (2016) sets out the national approach to diagnosis and makes the following observations:

- In 2012 34% of people had waited three years or more for a diagnosis after first raising concerns p.10.
- NICE guidance recommends that people should have a diagnostic assessment within 3 months of referral p.10.
- No formal statistics are collected on autism referrals p.11.

[10] Challenging Behaviour Foundation

[11] The National Institute for Health & Care Excellence (NICE) Quality Standard QS51

- In 2015 the Royal College of General Practitioners launched a training programme for its members to improve the diagnosis of autism and support

Autistic children and adults are waiting too long for diagnosis. Research indicates that, on average, the wait for children is over three and a half years whilst adults wait on average two years after seeking professional help. This can mean restrictions to accessing much needed support, leaving people at crisis point. On Wednesday 13 September 2017 Parliament debated autism diagnosis waiting times. A report around data is expected in 2019[12].

1.3 What is the impact of autism?

There are two areas of impairment affecting people with autism identified and widely accepted:

1. Social communication and interaction - for example, they may find it hard to begin or carry on a conversation, they may not understand social rules such as how far to stand from somebody else, or they may find it difficult to make friends.
2. Restricted, repetitive patterns of behaviour, interests or activities (including sensory behaviours) - for example, they may develop an overwhelming interest in something, they may follow inflexible routines or rituals, they may make repetitive body movements, or they may be hypersensitive to certain sounds.
   American Diagnostic and Statistical manual (DSM-5)

Everyone with autism experiences difficulties across these two distinct areas with varying severity and presentation and so an 'Autistic Spectrum' is referred to. Accordingly, some people with autism are able to live relatively 'unsupported' lives while others need a lifetime of specialist support.

DSM-5 has introduced 'dimensional elements' or 'specifiers' which give an indication of how much someone's condition affects them. This will help to identify how much support an individual needs and could include intellectual impairment, language impairment, genetic conditions and behavioural disorder.

People who receive a diagnosis are not automatically eligible for support. DSM-5 explains that 'severity' levels may vary by context and also fluctuate over time, that the descriptive severity categories should not be used to determine eligibility for, and provision of, services and that 'these can only be developed at an individual level and through discussion of personal priorities and targets'.

1.3.1 Effects on health and wellbeing

Children, young people and adults with autism will vary enormously, but they all share the two areas of impairment regarding social interaction and restricted patterns of behaviour described earlier to varying degrees.

[12] https://hansard.parliament.uk/commons/2017-09-13/debates/6F2DA047-3EA6-4E63-A793-E47A1EA2D786/AutismDiagnosis

Other effects may be:

- Limited language skills and/or difficulty understanding
- Unusually low or high sensitivity in one or more senses
- Epilepsy, ADHD, gastro-intestinal problems, mental health issues, motor difficulties, sensory issues and sleep problems in children and young people.

Given these effects having the appropriate support and services in place will have an effect upon education, employment, a healthy lifestyle, independence and future relationships all of which impact upon wellbeing. Unfortunately people can often see services as "inflexible and reactive … and a lack of knowledge about the ways autism might affect a person can limit the support they are offered" (SCIE).

As stated by SCIE, having "small amounts of practical and social support can benefit people with autism, and have the potential to mean that more intensive services are needed less often" as "some of the difficulties faced by people with autism could be addressed or reduced if low-level, often relatively inexpensive services, were provided promptly".

Prevention services can support people "who may find that support with social skills can prevent social isolation and attendant mental health difficulties" and can also help people with more complex needs for whom "intensive support within the home, coupled with good respite care, can prevent placement in expensive residential care" (SCIE).

The National Audit Office[13] research suggests that "supporting more people with high-functioning autism and Asperger syndrome quickly becomes cost neutral, and can potentially lead to long-term savings from higher tax incomes and reduced benefit payments as people are supported into employment. It also reduces mental health and criminal justice costs as people are supported before they reach crisis" (SCIE). The Government paper Work, health and disability green paper: Improving Lives (2017) states that "appropriate work is good for an individual's physical and mental health. Being out of work is associated with a range of poor health outcomes" and that "the longer a person is out of work the more their health and wellbeing is likely to deteriorate".

The National Audit Office also highlights "the potential benefits, for outcomes and budgets, of specialist care management teams for people with high-functioning autism and Asperger syndrome including:

- Find getting a diagnosis easier
- Lead more independent lives
- Are more likely to work
- Are less likely to have mental health difficulties

[13] National Audit Office (2009) *Supporting people with autism through adulthood report by the Controller and Auditor General (HC 556)* London: The Stationary Office

- Are more likely to have carers who are in work
- Are less likely to live in residential care

It should also be noted that some very able people with autism may never come to the attention of services as having needs because they have strategies to overcome any difficulties with communication and social interaction. Other people with ASD may be intellectually able but need support from services because the degree of social interaction impairment they have hampers their chances of employment and achieving independence. However our duties under the Care Act still mean that we need to "promote wellbeing through signposting to alternative services in the community such as voluntary organisations" (SCIE) to ensure we support people in "preventing or delaying the development of needs for care and support"[14].

1.3.2 Mortality

There is some evidence to suggest that adults affected by autism are more likely to die earlier than others within society. The Report Personal Tragedies, Public Crisis 2017 commissioned by Autistica highlights that many families and autistic individuals have raised concerns over early deaths in autistic people. According to the report new research confirms that autistic people die on average 16 years earlier than the general population. For those with autism and learning disabilities mortality may be more than 30 years premature.

A large study from Sweden in 2015 analysed a very large, high quality dataset to compare the general population, autistic people, and people with both autism and a learning disability. Key findings include:

- Autistic adults with a learning disability are 40 times more likely to die prematurely due to a neurological condition, with epilepsy the leading cause of death.
- Autistic adults without a learning disability are 9 times more likely to die from suicide
- Between 20% and 40% of autistic people also have epilepsy and this rate increases steadily with age in contrast to a one percent prevalence rate in the general population
- In the majority of autistic people who develop epilepsy, their seizures do not appear until their teenage years, much later than average. This suggests that the underlying triggers of epilepsy may be different in autism.
- After heart disease, suicide is now the leading cause of early death in adults with autism and no learning disability. The recent Swedish study found that adults with autism and no additional learning disability are over 9 times more likely (relative to a general population) to commit suicide.
- Multiple studies[15] [16] [17] suggest that between 30% and 50% of autistic people have considered committing suicide. One study found that 14% of autistic children experience suicidal thoughts compared to 0.5% of typically developing children.

[14] Department of Health (2014) 'Care and support statutory guidance issued under the Care Act 2014', London: Department of Health.

[15] Segers, M., Rawana, J. (2014). What do we know about suicidality in autism spectrum disorders? A systematic review. Autism Research, 5;7(4):507-21

[16] Raja, M. (2014). Suicide risk in adults with Asperger's syndrome. Lancet Psychiatry. 1(2), 99-101

[17] Balfe, M., Tantam, D. (2010). A descriptive social and health profile of a community sample of adults and adolescents with Asperger syndrome. BMC Research Notes, 3: 300

Another recent study of adults with Asperger Syndrome found that two-thirds of participants had lifetime experience of suicidal thoughts and a third of participants had planned or attempted suicide.

- The recent report from the Mental Health Taskforce[18] identified autistic people as at higher risk of mental health problems. Research indicates that 70% of autistic individuals have one mental health disorder such as anxiety or depression, and 40% have at least two mental health problems. When these issues appear alongside autism, mental health difficulties can go undiagnosed and untreated.

1.3.3 Access to generic/universal services

Due to a lack of specialist services for people with autism most people access generic services. Whilst in some ways this may be appropriate because of their presenting need at that particular point in time a lack of autism awareness by generic services can sometimes prove problematic.

Access to Primary Care Services is important if autistic people are to extend their life beyond the current trends. Poor take up of specialist, general health screening (breast, prostate and phlebotomy) needs to be addressed and specialists who are able to work with autistic people, when required, to make sure they are able to access these services and benefit from any interventions that may be put in place are needed[19].

Weight management is a key issue in reducing the incidences of cardiovascular disease and diabetes among this population. Evidence suggests that those with ASD may be "particularly vulnerable to obesity due to the behavioural, physical and psychosocial complications relating to their condition"[20]. Access to health services such as ophthalmology and community dental services are also areas of concern[21].

In April 2018 NHS England re-launched their Stopping Over Medication of People With a Learning Disability (STOMP) campaign which seeks alternatives to prescribing psychotropic drugs. According to NHS England "35,000 adults with a learning disability, autism or both are being prescribed an antipsychotic, an antidepressant or both without appropriate clinical justification. Long-term use of these drugs can lead to significant weight gain, organ failure and, in some cases, death"[22] further increasing the inequalities for autistic people.

Further knowledge of how specialist services could enhance the ability of autistic people to navigate available health and social care services is required and could include initiatives such as the expansion of the role of the Learning Disability Acute Liaison Nurses within secondary care.

[18] Hirvikoski, T. et al. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 207(5).
[19] Public Health England *Making reasonable adjustments to cancer screening*, 2012, p. 7
[20] Strahan, B. E. and Elder, J. H, (2013) "Obesity in adolescents with autism spectrum disorders, *Research in Autism Spectrum Disorders*, 7(12), p. 1497
[21] Vogan, V., Lake, J. K., Tint, A., Weiss, J. A and Lunsky, Y. (2017) "Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction", *Disability and Health Journal*, 10(2), p. 264
[22] NHS England (2018) NHS England urges more doctors and health care professionals to sign up to national pledge to stop overmedication for people with a learning disability, autism or both

The Social Care Institute for Excellence **SCIE** have identified the following barriers to receiving services affecting people with autism:

- A lack of awareness about autism and understanding of how it might affect each autistic person differently from some social care staff, other professions and society generally.
- The 'invisibility' of autism as a condition. People with autism do not have obvious physical signs of it, and are sometimes therefore thought to interact in ways that are simply odd, ill-mannered or alarming.
- Disability and benefits legislation and assessments, which sometimes seem shaped by a perception that a disability must have a physical manifestation. Receiving support can rely heavily on good social communication and social interaction skills when completing forms or taking part in assessments.
- The degree to which some people with autism can be talented and, particularly if they have no learning disability, very articulate. This can lead professionals to assume that they do not need social care or support.
- The blocking of people with high-functioning autism or Asperger syndrome from some social care services because they do not qualify for learning disability or mental health specific services.
- Generic services, such as those addressing drug and alcohol abuse, do not feel confident in offering a service and try to refer people with autism to specialised services that are scarce, and can be geographically or financially difficult to access. In Nottinghamshire the Asperger's team report that this can lead to referrals being bounced between services e.g. between drug and alcohol services and psychology services where neither feel that the primary need lies with them. A programme to upskill these generic services and provide them with the confidence to support people with autism may mitigate some of these re-referrals.
- Many social services are introducing generic teams, which have separate sections for initial assessment and for ongoing care. Generic assessments can result in services not being delivered to individuals because they do not meet the eligibility criteria in line with the Care Act 2014. However this may be due to the fact that it is more challenging to work with people affected by autism and to fully understand their needs during the assessment process due to communication difficulties and the time factor involved. Provision of specialist workers can enable people to articulate their needs but this can be time intensive. In Nottinghamshire our Asperger's Team provide this specialist support (see section below).

1.3.4 Specialist/autism specific services

In order to combat these barriers the National Institute for Health and Clinical Excellence (NICE) has published clinical guides on autism:

- **ASD in adults: diagnosis and management**
- **ASD in under 19's: recognition, referral and diagnosis**
- **ASD: management and support of children and young people**

The guides state that the local services (including health, mental health, learning disability, education and social care services) for autism should be coordinated by a multi-agency strategy group and that the coordination of care should be provided through local **specialist**, community-based multidisciplinary teams which should include professionals from health, mental health, learning disability, education and social care services.

The guidelines are not mandatory but the Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

1.4 Autism and gender

Five times as many males as females are diagnosed with autism. Research suggests that autism spectrum disorders are under-diagnosed in females, and therefore the male to female ratio of those who are on the autism spectrum may be closer than the 5:1 ratio. Baird et al (2006)[23] studied 57,000 9 to 10 year old children in South Thames and concluded that the prevalence of autism and related ASDs is substantially greater than previously recognised. Whether the increase is due to better ascertainment, broadening diagnostic criteria, or increased incidence was unclear. The Adult Psychiatric Morbidity Survey (APMS)[24], found a prevalence rate of 1.1% males compared with 0.2% female and the overall prevalence of autism was found to be 0.7%

One reason for the difference may be that it is much more difficult for females to gain a diagnosis of autism and that they are more likely to be misdiagnosed [25]. The study by Gould and Ashton-Smith suggested that because women and girls present differently from men and boys, diagnostic questions should be altered to identify women and girls with autism who might otherwise be missed.

Further evidence from both Mandy et al. (2012) [26] and Giarelli et al. (2012) [27] suggest that differences in symptoms of autism may exist between girls and boys that could contribute to under-recognition of autism in girls, which is consistent with NICE CG128 findings. Girls may have less repetitive stereotyped behaviour and fine motor impairment, and higher levels of emotional problems. Boys may be more likely than girls to show aggressive behaviour and hyperactivity.

A single-centre study[28] showed that compared with neurotypical developing children, young people with ASD were nearly 8 times more likely to express a desire to be other than their

[23] Baird et al (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP), The Lancet Vol. 368, No.9531 July 2006
[24] Brugha et al (2009) Autism Spectrum Disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey, NHS Information Centre
[25] Gould, J. and Ashton-Smith, J. (2011) 'Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum', Good Autism Practice (GAP), vol. 12, pp. 34–41
[26] William Mandy et al Sex Differences in Autism Spectrum Disorder: Evidence from a Large Sample of Children and Adolescents *Journal of Autism and Developmental Disorders July 2012, Volume 42, Issue 7, pp 1304–1313*
[27] Giarelli et al (2102) Sex differences in the evaluation and diagnosis of ASD among children *Disability and Health Journal Volume 3, Issue 2, April 2010, Pages 107-116*
[28] Gender Identity Issues Linked to Autism, ADHD *Medscape* Mar 17, 2014

biological sex — a phenomenon the authors describe as "gender variance." Those with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) had more than 6 times the odds of communicating gender variance, according to parent-reported data.

1.5 Autism and learning disabilities

Around a third of people with a learning disability may also be autistic[29]. Explanations of why these findings are so variable, and the reliability of the figures, can be found in both Emerson and Baines (2010)[30] and in Fombonne et al (2011)[31].

One of the key issues for adults with autism is that they risk falling into the gap between services for people with learning disability and mental health conditions, so could struggle to receive the support they need[32]. Taylor and Marrable (2011) found that difficulties can be even greater for autistic people who display behaviours that challenge services, or who have needs that cross the boundaries of several different services. Individual professionals may be extremely helpful, but the system itself is seen as ill-informed, complex and set up in ways that exclude or alienate people with autism. Autism is a developmental disorder and not a mental health problem. However, people are more likely to receive support if they also have a co-occurring condition such as a learning disability which has been identified in childhood or a mental health problem. In addition, if an adult with autism does not receive the support they need for this condition they are more likely to develop a mental health problem. Low level support at the right time could prevent this from arising and lead to better outcomes for the individual as well as reducing the economic and financial implications associated with supporting more complex needs. It is therefore vital that diagnosis is received to enable preventative services to be put in place at the earliest opportunity.

1.6 Autism and Black and Minority Ethnic (BaME) Communities

A report entitled 'Diverse perspectives: the challenges for families affected by autism from Black, Asian and Minority Ethnic communities' carried out by the National Autistic Society 2014 states that all families affected by autism experience a struggle when trying to get a diagnosis, access the services they need and integrate their child with their local community. However, they also found that certain additional challenges are more prevalent within BaME communities.

Some of the challenges relate to the communities themselves and include little knowledge about autism or beliefs that it is a curable condition. Stigma can lead to feelings of isolation, shame and blame for families. Families can also feel a responsibility to cope with their child's autism independently or have negative preconceptions of healthcare services. These

[29] https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx
[30] Emerson, E. and Baines, S. (2010) 'The estimated prevalence of autism among adults with learning disabilities in England, Stockton on Tees: Improving Health and Lives.
[31] Fombonne, E., Quirke, S. and Hagen, A. (2011). Epidemiology of pervasive developmental disorders. In Amaral D.G., Dawson G. and Geschwind D.H. eds. (2011) *Autism spectrum disorders*. New York: Oxford University Press, pp. 90 – 111.
[32] Taylor, I. and Marrable, T. (2011) Access to social care for adults with autistic spectrum conditions. SCIE

problems demonstrate a particular need for service providers to be accessible to, and engage with, people from local BaME communities.

Further issues exist around the accessibility of services such as information not being available in families' chosen languages and services not being tailored to, or sensitive of, the specific needs of local communities. Health and education professionals have demonstrated low levels of autism awareness as well as a lack of cultural competence leading to misunderstanding of parents and carers. As a result, families have had poor experiences of services which discourage them from accessing them leading to further isolation.

In order to address these issues, the report recommends a number of actions, to be taken by Local Authorities and Clinical Commissioning Groups:

- consult families from BaME communities about their specific needs when commissioning autism services
- ensure that the needs of BaME communities are included in the autism chapter of the Health and Wellbeing Board's Joint Strategic Needs Assessment
- record the number of diagnoses of autism in people from BAME communities and whether people from BaME communities are using local autism services
- raise awareness and understanding of autism in local BaME communities, where needed
- ensure service providers' information on autism and their services is readily available in appropriate languages and is promoted to BaME communities
- commission services that are accessible for local BaME communities, including in appropriate locations and at appropriate times
- commission peer support forums for parents and carers from local BaME communities and, where appropriate, tailored support services
- provide advocacy, translation and interpretation services for families from BaME communities who require support during and following diagnosis of autism.

1.7 Autism and older people

A report by the National Autistic Society [33] has found that older people with autism face significant challenges in older age such as the ability of professionals to recognise and support age related conditions in people with autism. Some of these challenges are common to adults with autism across all age ranges but become more pressing in older age – for example, the need for specific training amongst healthcare professionals in the presentation of older people with autism and the need to combat social isolation.

Research into the issues faced by older people produced the following recommendations for Local Authorities and Clinical Commissioning Groups (CCGs):

[33] http://www.autism.org.uk/about/adult-life/ageing.aspx

- train staff working in older people's services in autism, and include training in autism as a contractual requirement for older people's service providers
- follow the NICE guidance on autism in adults
- consider volunteer-led models to support older people with autism in developing local commissioning plans, and fund such services to meet need
- gather information on the numbers of people over 65 with autism in the local area, as recommended by the Autism Act Statutory Guidance, and include these figures in Joint Strategic Needs Assessments (JSNAs)
- ensure CCG's are developing post-diagnostic support, including counselling from counsellors trained in autism.

As the population ages, and more people with varying disabilities are living longer, the prospect of living with long term conditions is expected to rise. Services currently available to those over 65 have been in place for many years and it has not been considered how ageing people with autism can be accommodated within the traditional model of residential care. In addition, many people with autism live with relatives or parents who are themselves ageing. It is not clear, therefore, how current systems will manage the demand and changing needs of people affected by autism as they age.

1.8 Economic impact

Employment impacts upon everyone's health and wellbeing, and there is no research to date that suggests people with autism are affected significantly differently. The 2011-12 Office for National Statistics (ONS) Labour Force Survey showed that those who are unemployed report a larger degree of dissatisfaction (more than 50%) with life than those who are in employment.

A large proportion of the cost of supporting people with autism is accounted for by lost employment. This significantly impacts not only on the people with autism but as Knapp et al (2007)[34] suggest also on wider society and therefore the UK economy. Their findings suggest that the lifetime cost for someone with high-functioning autism is near to £3.1 million and £4.6 million for someone with low-functioning autism. This means that many adults with autism are dependent on benefits, and that UK employers are not benefiting from the skills and talents adults with autism can offer in the workplace (Department of Health).

Hendricks (2010)[35] identified that obtaining employment for people with autism is particularly difficult because of their unique communication and social impairments, and acknowledges the ongoing high unemployment rates amongst people with autism identified by the National Autistic Society in 2008. The interactional difficulties associated with autism account for the biggest vocational hurdle, and in her interviews with people with autism,

[34] Knapp, Martin, Renee Romeo & Jennifer Beecham (2007), *The Economic Consequences of Autism in the UK*
[35] Hendricks D. (2010) Employment and adults with ASD: challenges and strategies for success Journal of Vocational Rehabilitation 32

communication and social difficulties with supervisors and co-workers consistently emerge as a primary hindrance to job performance.

Lopez et al (2013)[36] found that barriers to employment still included a lack of reasonable adjustments and a lack of understanding about autism from employers. They concluded that with the right support, autistic people can make excellent employees. They also found that many people with autism who are in work are employed part time, and in roles that do not reflect their qualifications. This may partly be a reflection of the need for work which does not cause overload. The National Audit Office published a paper "Supporting people with autism through adulthood" which suggests that in order "to allow people with autism to fulfil their potential in the workplace, training and support are needed not just for the individuals concerned, but also for their employers and colleagues" as people found that a "lack of understanding of autism amongst employers" was a "significant barrier to work". Provision of opportunities for their staff to be more aware of autism and how it might affect people in the workplace still require development. The development of specialist traineeships, apprenticeships and internships will assist people with autism to become "work-ready" and reduce the cost to organisations. "Supported internships offer promising routes into work for people with learning disabilities and in some areas have led to employment rates of 65 per cent"[37]. Identification of approaches that can create an environment where support can easily be obtained and maintained will make a significant different to people's life employment chances.

A National Autistic Society report by Laura Simons (2007) "Think Differently, Act Positively: Public Perceptions of Autism", highlighted that while the overall employment rate for disabled people is 48%, estimates suggest that only 15% of all people with autism are in full-time paid employment. The report estimated that only 12% of people with high-functioning autism are in full-time employment and 6% part-time.

For young people going through the transition from Children's to Adult Services, the Care Act 2014 imposes a duty on the authority to provide support at an early stage (14yrs).The National Autistic Society report *Moving on up? Negotiating the transition to adulthood for young people with autism (2006)* found that:

- Despite the fact that many people with autism have skills which could be valuable to employers, only around 15% of people with autism are in full-time employment. There is a lack of awareness and knowledge of autism among potential employers and Jobcentre Plus staff, which can result in poor decision-making and job outcomes for adults with autism
- There is a lack of sufficient knowledge and awareness of autism by those staff working in health, social care, benefits and employment services.

[36] Lopez B. et al (2013) Barriers to employment in autism: future challenges to implementing the Adult Autism Strategy, Portsmouth: Portsmouth University

[37] Centre for Social Justice (2017) Rethinking Disability at Work

Nicholas et al (2017)[38] carried out research focusing on transitional and vocational issues in ASD. Using a qualitative analytic approach, key themes were identified which highlighted the need to build employer capacity relative to employing persons with ASD and enhance support resources for adults with ASD and their families.

The increased use of technology across all business could also lend itself to enabling people with autism to work. Initiatives including "training individuals using selected iPad applications to help with organization, scheduling, and social interaction"[39] and "work-related behavior training"[40].

1.9 Autism and social isolation

People with autism are at high risk of social isolation and exclusion. The characteristics associated with autism mean that developing friendships and social networks can be very difficult and stressful. As a result, anxiety increases and individuals often either exclude themselves or find themselves excluded, and so have little contact with the outside world. Understanding and communicating with other people is particularly difficult and can leave people feeling very lonely. As many as 79% of autistic people and 70% of their families feel socially isolated (Bates, P. and Davis, F. A.2004)[41], and 81% of young people with autism believe they spend less time socialising than their peers Ambitious about Autism.

1.10 Autism and the Criminal Justice System

ASD can increase vulnerability and may lead to people being exploited and either being led to commit crime themselves or becoming a victim of crime. Also the incidence of disability hate crime against persons with autism may well be severely under-reported due to their communication difficulties and failure to understand what is and what isn't the social norm.

Crane et al (2016)[42] found in an online survey of 394 police officers that just 42% of the officers contacted were satisfied with how they had worked with individuals with ASD. The reasons for this varied. Although officers acknowledged the need for adjustments, organisational and time constraints were cited as barriers. Whilst 37% of officers had received training on ASD, a need for training tailored to policing roles (e.g. frontline officers, detectives) was identified. Police responses are discussed with respect to the experiences of the ASD community (31 adults with ASD, 49 parents), who were largely dissatisfied with their experience of the police and echoed the need for police training on

[38] Nicholas D.B. et al (2017) Evaluation of employment support services for adults with ASD. Autism Jun 1
[39] Chen, J. L., Leader, G., Sung, C. and Leahy, M. (2015) "Trends in employment for individuals with autism spectrum disorder: a review of the research literature" *Review Journal of Autism and Developmental Disorders 2*, p. 122
[40] Chen, J. L., Leader, G., Sung, C. and Leahy, M. (2015) "Trends in employment for individuals with autism spectrum disorder: a review of the research literature" *Review Journal of Autism and Developmental Disorders 2*, p. 122
[41] Bates, P. and Davis, F.A. (2004) Social capital, social inclusion and services for people with learning disabilities. Disability and Society, 19(3):195-207
[42] Crane, L. et al(2016) Experiences of ASD and policing in England and Wales, Journal of Autism and Developmental Disorders 2016, Vol. 46 (6)

ASD. Those that do enter the system as victims are often deemed as not being a credible witness, leading to failures to prosecute.

Dein and Woodbury-Smith (2010)[43] conclude that:

- Autism could also render someone highly vulnerable if they come into contact with the criminal justice system
- Within the criminal justice system, police officers, probation services and courts are frequently unaware of communication challenges relating to autism, leading to overly heavy-handed responses to incidents.
- The authors highlight the need for further research into this complex issue, and suggest that those who work within the criminal justice system should be aware of and have access to training and/or appropriately trained colleagues in order that the needs of this particularly vulnerable group might be more effectively met.

2. Size of the issue locally

Based on the application of national prevalence rates to the local population estimated figures for the number of people with ASD across the county are shown in the table below. Mechanisms for recording autism are not consistently available across health and social care meaning actual figures are currently unavailable. As mentioned earlier there is also an under-diagnosis within certain groups such as older people and females (as seen in the difference between the figures in the table below) which is also likely to increase the figures in the future as improvements to the diagnostic pathway are made.

In Nottinghamshire during the past year (February 2017 to April 2018) the Mid-Notts CCGs have received and approved 29 referrals for diagnosis. No data is available for the other areas of the county.

Table 2: Estimated prevalence of autistic spectrum disorders in Nottinghamshire

District	Males	Females	Total
Ashfield	862	102	964
Bassetlaw	819	94	913
Broxtowe	813	93	906
Gedling	812	98	910
Mansfield	747	87	834
Newark and Sherwood	844	98	942
Rushcliffe	810	95	905
Total	5715	667	6382

Source: PANSI v.10 and POPPI v. 10

The table reflect the marked gender difference in the numbers of people with autism, there being significantly more males than females

[43] Dein K. and Woodbury Smith M. Asperger syndrome and criminal behaviour. Advances in Psychiatric Treatment Jan 2010, 16 (1) 37-43

Social care services are currently in the process of implementing a new recording mechanism for autism meaning that figures for those receiving adult social care will be more accurate in the future and as such will allow us to assess the extent of met need across our population including by ethnicity, age and gender. Further work is required to enable data to be collected and shared from CCGs in line with NICE recommendations (see Autistic people will receive better care if GPs develop a national register, says NICE)[44].

The table below shows the likely projected increase in the number of people with ASD. This and the planned improvements in the diagnosis of autism will result in an overall increase in the number of people with autism of all ages being known to services. .

Table 3: People in Nottinghamshire aged 18+ predicted to have autistic spectrum disorders (ASD), projected to 2035

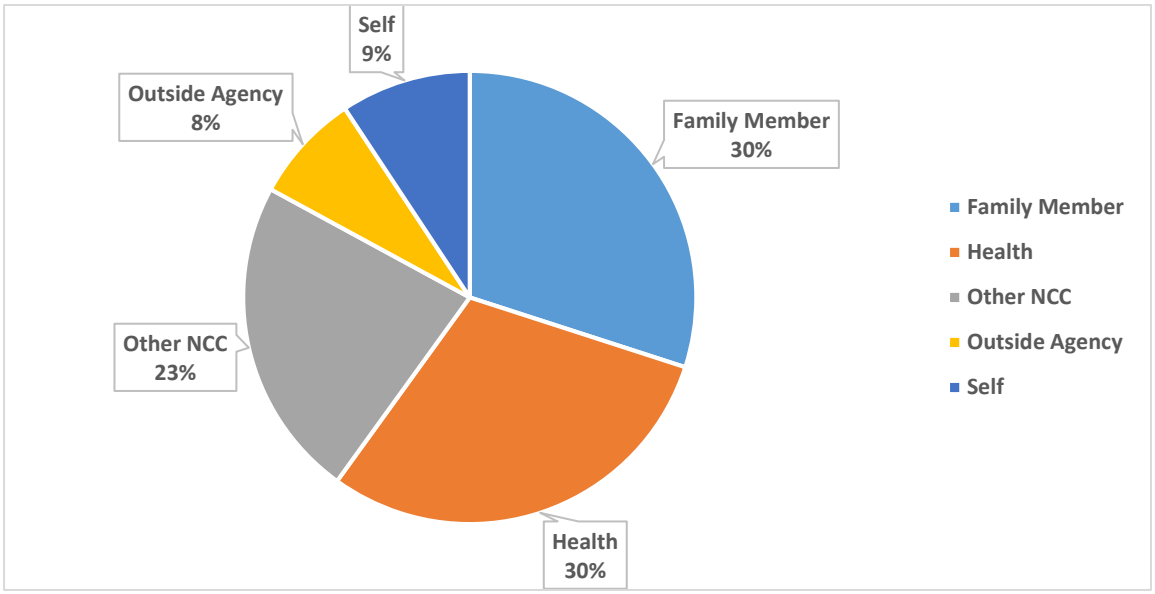
Year	2017	2020	2025	2030	2035
People aged 18-24	892	858	856	957	966
People aged 25-34	1,226	1,243	1,230	1,166	1,204
People aged 35-44	1,133	1,152	1,206	1,250	1,241
People aged 45-54	1,291	1,228	1,134	1,136	1,192
People aged 55-64	1,075	1,160	1,235	1,180	1,096
People aged 65+	1,572	1,666	1,851	2,075	2,264
Total population aged 18+predicted to have ASD	7,187	7,306	7,513	7,764	7,963

Source: PANSI v.10 and POPPPI v.10. The prevalence rates have been applied to ONS population projections of the 18+ population to give estimated numbers predicted to have autistic spectrum disorder 2035.

Support is available for adults from the Nottinghamshire County Council (NCC) Asperger's Team. Currently the team report an average of 160 new referrals per financial year however an improved diagnostic pathway as detailed in 1.2 above would lead to an anticipated increase. The following chart shows the percentage of adult referrals to the team and their source.

[44] Autistic people will receive better care if GPs develop a national register, says NICE

Figure 1: Source of referrals to the Asperger's Team 2012 to 2016



Source: Nottinghamshire County Council Asperger's Team

Of the referrals received by the team 28% were for females and 72% for males. Further only 2% of referrals were for people aged 65+ and 9% for people aged 55+ which falls in line with expectations given the under-diagnosis in this population group. Unfortunately, the team does not currently record ethnicity of the people referred to them or the outcomes of referrals other than on individual service user records.

In addition to the caseload of the Adults with Asperger's Team the Transitions Team also support a number of young people and their families with ASD through their transition to adulthood. At present (June 2018) there are 37 young people on the Transition Team waiting list who are identified as have ASD as their primary or co-presenting need. Of these 14 also have a learning disability, 2 have mental health needs, one a physical disability and 1 oppositional demand avoidance.

3. Targets and performance

Adult Social Care Outcomes Framework (ASCOF)

The Adult Social Care Outcomes Framework (ASCOF) measures how well care and support services achieve the outcomes that matter most to people. The measures are grouped into four domains which are typically reviewed in terms of movement over time. Data is provided at council, regional and national level. Although the ASCOF does not specifically measure outcomes for people with autism, highlighted within the 2016-17 document 5.7% of adults in England receiving long-term learning disability support were reported as being in paid employment in 2016-17 and a proportion of these people will also have autism. The North West, ***East Midlands*** and West Midlands have the lowest proportion of adults with a learning disability in paid employment at 4.2%. *Source, p23, SALT, NHS Digital*

Think Autism - Fulfilling and Rewarding Lives 2014
This sets out to update the government's strategy and is discussed in more detail within this chapter.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

Autism Self-Assessment Framework (SAF)
See **Appendix 1** for the Nottinghamshire County Council Autism Action plan which incorporates the priorities identified by the SAF.

4. Current activity, service provision and assets

Pre and post diagnostic support (generic services):
As already stated, people with autism can find it hard to obtain a diagnosis and often find that appropriate education, medical and social care services are consequently limited or delayed. It is therefore vital that "prompt advice, practical support and help finding the right ongoing support is a key part of early intervention" (SCIE). The NICE guidelines for Autism spectrum disorder in adults: diagnosis and management state that interventions may include:

- Social learning programmes
- Structured training programmes around life skills
- Structured leisure activity programme
- Anger management
- Anti-victimisation interventions
- Supported employment (including CV writing, job applications, preparing for interviews, training, job matching)
- Medication

Locally the following services offer pre and post diagnostic support:

1. Customer Service Centre (CSC) Tel. no 0300 500 80 80
Nottinghamshire County Council provides access to all its services through trained advisors at their Customer Services Centre (CSC). Staff are available to provide information over the phone and, if needed, enable specialist teams to take any issues forward. Members of the public can access this service directly and be referred to the dedicated Asperger's Team where appropriate.

2. NottsHelpYourself
The NottsHelpYourself website provides information about a whole range of services that are available in the county and nationally. The information can be filtered using a number of options including autism. The site works on tablets and smartphones and can be accessed at libraries where staff are available to provide support. A search on NottsHelpYourself for organisations working with people with autism results in approximately 220 different organisations/groups offering a service specifically for people with autism including voluntary and community organisations. There are also over 6000 general listings which may also be of interest.

Diagnostic services (autism specific):

1. Asperger Service, Nottingham City Council

Due to the crossover of service boundaries and GP registration some residents of Nottinghamshire County may access services via Nottingham City Council who provide diagnosis, treatment and signposting for adults with, or seeking a diagnosis of, autism spectrum disorder and who do not have a diagnosis of intellectual disability. Services are available to all adults over 18 if they live in Nottingham City or have a Nottingham City GP. The service is utilised on an ad hoc basis by county CCGs looking for patient diagnosis however this does not form part of a core or standard contract and is commissioned on a case-by-case basis.

Post diagnostic support (autism specific services):

1. Nottinghamshire County Council (NCC) Asperger's Team

The Asperger's Team works with people with a diagnosis of Asperger's or high-functioning autistic spectrum disorders without a learning disability. Their role involves assessing the needs of the person and then helping them to access that support, which will not necessarily involve Social Services funding. They are able to provide support for up to 12 weeks.

People contacting the team are interviewed in their own homes or a similar environment (e.g. day room in an older people's centre or library) where possible, according to their preference and safeguarding needs. The team also holds regular 'Community Meetings', a service provided in a variety of locations which enables the public to book an hour's meeting with Promoting Independence Workers to get an initial idea about whether any formal assessments might be needed, and to assess needs and give advice and support. These are designed to be informal settings which enable potential service users to feel able to communicate with the team about their needs.

2. Nottinghamshire Local Offer - Children and Young People

The SEND Local Offer forms a sub-section of the NottsHelpYourself website and brings together helpful and useful information for children and young people with Special Educational Needs and Disabilities (SEND), from birth to 25 years, and their families. The information is contained within a website, which allows a search for services and provision within the community and Nottinghamshire as a whole. This will cover public services that are available within:

- Education: e.g. nurseries, playgroups, schools and colleges as well as support services like educational psychologists, early years and early intervention workers
- Health: e.g. GPs, paediatricians, school nurses and therapists
- Social care: e.g. respite services and children's disability services.

The site enables people to find out what support and services are available in the voluntary and private sectors, for example from charities and disability groups.

In order to make information more accessible a number of videos are available on the website which explain the options and opportunities on offer to help with the transition stage. The videos can be viewed here.

3. Nottinghamshire Learning Disability and Autism Partnership Board

The Board meets every two months and is attended by service users, carers, County Council Members, service providers and officers from Nottinghamshire County Council and Health Services. The meeting provides an opportunity for people to work together to make services better by sharing information and experiences to help plan for the future. The agenda reflects national and local developments that may affect people with learning disabilities and/or autism. It also encourages service users and carers to raise issues and topics for discussion. Several of the Board members have become Experts by Experience who contribute regularly to training and co-production activities relating to learning disabilities and autism.

4. Nottinghamshire County Council's i-works team

People who live in Nottinghamshire and have a learning disability or Asperger's can be supported by the i-works team who will:

- Look at their skills, interests and qualifications
- Find jobs that they might like to do
- Explain what will happen with benefits if they get paid work
- Give them the opportunity to try out jobs to see if they like them
- Continue to provide support when they find a job to help them stay there

In January 2018, 483 people were being assisted: 131 were in permanent work, 132 in training for work, 44 in temporary paid work, and 11 in voluntary placements. The remaining 170 people were on hold (for a variety of reasons including waiting lists and readiness to engage), having initial contacts, marketing or profiling for them. The team have also assisted individuals to get a diagnosis when this has not been received when first contacting the team by referring back to GP services for this. The iWorks team has suggested that it may be necessary to have more interventions from experienced officers to assist with enabling people affected by autism to gain support at the earliest opportunity.

5. Autism East Midlands

Autism East Midlands provide a full range of services dedicated to people affected by Autism. In this regard their views around how services should or could be developed is an important element of thinking around services alongside their connections to individuals and families within this field. The organisation has developed a range of good practices guides to support local authorities and the NHS with implementing the Autism Strategy and Guidance.

6. Support Groups

A full range of support groups can be accessed via the Notts Help Yourself website.

7. Autism Connect

Autism Connect was originally developed with funding from the Department for Education and was expanded to have a national focus with Autism Innovation project funding. Through Autism Connect it is possible to connect with like-minded people, share experiences, and ask and answer questions within the autism community. Additionally users can find, rate and review local services as well as autism friendly venues. Also referenced are many free information sheets on aspects of autism. The events and calendar section enables users to find and add details of local events and activities.

8. Nottinghamshire County Council Co-production Team

Working with the Asperger's team, the Co-production team have set up community 'clinics' where adults who are on the Asperger's spectrum are signposted to community groups/activities that meet their needs with regards to social and well-being development/opportunities. In the year 2017-18 26 people were seen across three clinics, 5 people went on to require a full social care assessment and the remainder were referred to reablement or the Notts Enabling Service (NES).

Training:

1. Provision of Training

In line with actions highlighted with the Self-Assessment Framework (SAF) basic training around autism is now available to all Nottinghamshire County Council members of staff, alongside all health partners, voluntary sector agencies and independent advisors via an e-learning package. The e-learning package is publicly available and in the year April 2017-March 2018 339 people viewed the course online with a further 170 NCC staff members completing the training through Learning Pool.

- Positive about Autism is a training company providing workshops on autism. Their training is active, visual and fun and reflects a positive style and positive philosophy. http://positiveaboutautism.co.uk/index.html
- A half-day course for foster carers is delivered in co-operation with Autism East Midlands.
- In addition Nottinghamshire County Council have e-learning access to the Intermediate Programme developed by Social Care Excellence (SCIE)

Nottinghamshire County Council (NCC) plan to develop a classroom programme aimed initially at NCC staff, with the possibility of extending to external related agencies.

2. Nottingham University Hospitals (NUH)

Autism Awareness training and Autism Champions sessions have been delivered by Autism East Midlands at NUH. Originally Department of Health funded, the Nottingham Hospitals Charity has continued to support the training. Autism training is not mandatory but at NUH has been integrated wherever possible. The uptake has been excellent, in many cases oversubscribed, demonstrating that there is clearly a need that is resonating with clinical colleagues. The report below gives useful insight into the hospital experience as described by people with autism. Westminster Commission on Autism

5. Evidence of what works

Service Delivery

A House of Commons Briefing Paper Autism - overview of UK policy and services (Parkin 2016) gives a comprehensive picture of policies and services in the UK and notes that successive Governments have supported initiatives to improve outcomes for people with autism. The documents listed below are some of the key strategic influences to be considered in relation to services for people with autism.

The NICE Autism Spectrum Disorder Interactive Flowchart provides information on the identification, assessment and management of ASD in adults and children.

Think Autism 2014 sets out to update the government's strategy for improving outcomes for adults with autism in England, first set out in Fulfilling and rewarding lives 2010 to help improve the quality of life for people with autism. Think Autism states that people with autism need to have access to a clear pathway to diagnosis and know that this pathway is aligned with care and support assessments, and that there is post-diagnostic support available even if the person does not meet social care criteria. Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families. The review highlights fifteen priority challenges for action which have been identified by people with autism, carers, professionals and others who work with people with autism.

Assistive TechnologyResearch Autism has produced guidance on the range of technologies available and how they enhance the lives of people affected by autism. Many have been evaluated in terms of their effectiveness and may be seen to reduce anxiety and enable easy access to relatives/carers when difficulties arise. Some are deemed to be more effective than others and can assist with the reduction of behaviours that may be displayed as a result of misunderstandings[45].

Health Promotion

A Progress Report on Think Autism 2016 sets autism and the aims of the Think Autism strategy in the context of government reform to deliver quality care to those who need it and make a positive impact on people's health in an efficient way; be a core part of health and care delivery; make sure that people have a good experience of care and services; prevent people from having episodes of crisis; join up better the NHS and social care, and other local partners. Within each section, progress has also been highlighted from the latest local authority area autism self-assessment exercise.

Strategic

The National Autistic Society Guide for local authorities and local health bodies in England is a quick reference for local authorities and the NHS, setting out the basics of what they must do to implement the different aspects of the adult autism strategy and statutory guidance, as well as what they need to do next, once they have the basics in place. Also included are examples

[45] http://researchautism.net/autism-interventions/our-evaluations-interventions

of good work already underway, showing how a few straightforward, practical measures can have a positive impact on the lives of adults with autism. Examples include:

Supporting Autistic Adults, James Lang, The National Autistic Society Centre Strategic Lead, explains how their adult services aim to offer flexible support designed around the needs of the people they support.
http://network.autism.org.uk/good-practice/case-studies/supporting-autistic-adults

Dr Anna Remington and Prof Liz Pellicano outline the results of research conducted by the Centre for Research in Autism and Education (CRAE) in collaboration with Deutsche Bank UK which recently launched an internship programme for autistic graduates.
http://network.autism.org.uk/good-practice/evidence-base/internship-autistic-graduates-deutsche-bank-uk

Training
Nottinghamshire Healthcare NHS Foundation Trust
The Trust has made a series of videos about Autism and Communicating in the Public Sector which clearly identify the difference made by autism. They are made especially for people working in GP surgeries, Social Care, Police, Job Centre's, Schools and Universities.

6. What is on the horizon?

Table 4 below shows the expected increase in people living with autism in Nottinghamshire in the future. Whilst the numbers may not be significantly different to those currently, having a greater number of autistic people within our older people's services does present additional requirements for training around, and consideration of, comorbidities alongside autism.

Table 4: People in Nottinghamshire aged18+ and over predicted to have Autistic Spectrum Disorders (ASD), projected to 2035

Year	2017	2020	2025	2030	2035
People aged 18-24	892	858	856	957	966
People aged 25-34	1,226	1,243	1,230	1,166	1,204
People aged 35-44	1,133	1,152	1,206	1,250	1,241
People aged 45-54	1,291	1,228	1,134	1,136	1,192
People aged 55-64	1,075	1,160	1,235	1,180	1,096
People aged 65+	1,572	1,666	1,851	2,075	2,264
Total population aged 18+predicted to have ASD	7,187	7,306	7,513	7,764	7,963

Source: POPPI v.10 and PANSI v.10 The prevalence rates have been applied to ONS population projections of the 18+ population to give estimated numbers predicted to have autistic spectrum disorder to 2035.

Table 5: People in Nottinghamshire aged 65 and over predicted to have ASD in the future, projected to 2035

Year	2017	2020	2025	2030	2035
Males aged 65-74	821	830	835	932	995
Males aged 75 and over predicted to have ASD	571	646	806	911	1,015
Total males aged 65+ predicted to have ASD	1,391	1,476	1,642	1,843	2,011
Females aged 65-74 predicted to have ASD	97	97	97	109	117
Females aged 75 and over predicted to have ASD	85	93	111	123	136
Total females aged 65+ predicted to have ASD	181	190	209	232	253
Total population aged 65+ predicted to have ASD	1572	1666	1851	2075	2264

Source: POPPI v.10.The prevalence rates have been applied to ONS population projections of the 65 and over population to give estimated numbers predicted to have autistic spectrum disorder to 2035.

Experts by Experience Training – evidence of effectiveness

Whilst there has been extensive research around interventions and clinical effectiveness of current treatment plans for those suspected as being affected by autism, or with a clinical diagnosis, at present there is little research and evidence to support Experts by Experience as a means of enabling those working across the autism field to be more effective in their interactions with those affected by autism. Further research will need to be conducted in this field to enable any learning to be more widely recognised and adopted across a range of agencies. In Nottinghamshire, the Autism R Us CIC provide a half day course for staff and partners based on their own user experiences.

Five Year Forward View

This NHS England document represents the shared view of the NHS' national leadership, and reflects an emerging consensus amongst patient groups, clinicians, local communities and frontline NHS leaders. It sets out a vision of a better NHS, the steps to be taken to achieve this and the actions needed from others. In terms of autism the primary relevance regards the proposed improvements to mental health services to provide better access to care and support.

Nottinghamshire Sustainability and Transformation Plan 2016-21

Sustainability and Transformation Partnerships (STP's) have been charged with making a difference to everyone's life through sustained developments across the health and social care sectors and are designed to facilitate more streamlined and affordable services going forward. The goal outlined for the people of Nottinghamshire is that they lead healthy lives and be independent and well. To do this the STP aims to improve the physical and mental wellbeing of people and simplifying the way people get support. As well as the general messages around improving health and wellbeing one of the key areas of focus is to have prompt access to mental health services before a crisis occurs which is crucial for people with autism.

Transforming Care

NHS England's Transforming Care programme set out to improve the quality of life of people with learning disabilities and or autism by substantially reducing the number of people placed in specialist hospitals, reducing the length of time those admitted spend there, and enhancing the quality of both hospital and community settings.

Transforming Care Partnerships

The partnerships are led by local commissioners of health and social care (Clinical Commissioning Groups and Local Authorities) working closely with specialist hospitals and social care providers, GPs, general hospitals and other agencies with whom the people come into contact such as the Police.

TCP's are responsible for addressing the needs of children, young people and adults with a learning disability and/or autism who:

1. display, or are at risk of developing, self-injurious or aggressive behaviour, not related to mental ill health. Some of these people may have a specific neuro-developmental syndrome where there may be an increased likelihood of displaying behaviour that challenges.
2. have, or are at risk of developing, a mental health condition such as anxiety, depression, or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.
3. display, or are at risk of developing, risky behaviours which, if carried out with mental capacity, are illegal and which could lead to contact with the criminal justice system. This could include behaviour such as property damage, fire-setting or abusive, aggressive or sexually inappropriate behaviour to others.
4. have lower level support needs related to disability or illness but who are from disadvantaged backgrounds or troubled families where they experienced early life trauma or problems with attachment and bonding and who display or are at risk of developing a tendency to display, challenging behaviour, including behaviours which may lead to contact with the criminal justice system as well as experiencing fragile mental health.

At a local level the programme has been led by Nottingham City CCG working in partnership with the two local authorities (Nottingham City and Nottinghamshire County) and all other CCGs in the County. The focus of the partnership has been working to enable half of the 76 people from the area who are currently specialist hospital inpatients (and may have been for several years) to be discharged from hospital and to prevent other people being admitted unnecessarily.

The Transforming Care Programme set out with four areas of action:

- Early Intervention
- Prevention of Crisis
- Addressing Crises
- Effective Discharges

Early Intervention and Preventing Crises

A diagnosis of autism and a functional analysis of behaviour is essential for adults with autism who display challenging behaviour as they can suffer from being misunderstood. Behaviour must be regarded as being a form of communication and understood as a way in which the person is attempting to meet their own needs in daily life. Applied Behavioural Analysis (ABA) can offer an understanding of the behaviour and from this a person can start to be helped to have their needs met in different ways. Professionals with the ability to offer ABA are not readily available locally which is true across the country: there is a need for more training in ABA at advanced levels. Families of adults with autism also need to have access to information about, and training on, how to understand a relative with a tendency to display challenging behaviour and how to support them proactively.

Addressing Crises
The Nottinghamshire TCP has been looking at how a better response can be offered in a crisis to avoid people being inappropriately admitted to hospital for assessment and treatment and as a result losing their homes and remaining on a hospital pathway, being transferred to locked rehabilitation or secure inpatient services. Discussions are taking place with the Police to improve the impact of the experience when a person with a learning disability and/or autism comes into contact with the police. This is in addition to existing work by the Criminal Justice Liaison and Diversion Team who have specialist workers for people with learning disabilities and/or autism.

Effective Discharge
Many people have lived in hospital for years due to a lack of suitable and effective community support. The TCP has worked hard to enable the discharge of these people as they become ready for discharge and to prevent the inappropriate admission of others. This has required the development of more services and support in the community. As this has happened, hospital beds are being closed permanently.

Service Developments
The following developments have been initiated by the programme, some of which are still in the pilot stage of development and which will benefit one or more of the four areas of action

- Improving professionals' understanding of positive behavioural support through a programme of cross-organisation training
- The existing Intensive Community Assessment and Treatment Team (ICATT) has been enhanced to provide a higher level of staffing in order to increase its scope to operation
- Two 'Unplanned Care' beds have been block-funded in a care home to enable placements of people by ICATT to avoid an inappropriate admission.
- Reasonable adjustment to a mental health crisis housing service so that it can be accessed by people with autism or with mild learning disabilities
- Provision of a specialist advocacy service for people at risk of being admitted to hospital, or already admitted, to better hear the voice of the people concerned
- 27 new step-down beds have been or are being developed in care homes for people leaving hospital or who need to avoid hospital admission
- A new Community Forensic team has been created to support people with learning disabilities and/or autism leaving hospital with a history of offending
- A contract for a new service model has been entered into with a specialist support living provider to support people with autism who have a history of offending change their risk behaviours

Additionally to the service developments, some care and support providers have been reviewing the way they provide services to people who display challenging behaviour and considering how to provide their staff with more effective training.

7. Local Views

Access to services

<u>Nottinghamshire County Council (NCC) Asperger's Team</u>
Consultation with the NCC Asperger's Team, which works with people aged 18 plus and their families, indicated that from their perspective, having large waiting lists with very long waits is not ideal. When taking into account the often longer time it takes to work with individuals and their

families because of their autism, the wait and uncertainty can add to their distress and ability to cope. As a result the team recruited additional staff to the team to reduce this likelihood.

Bassetlaw Clinical Commissioning Group (CCG)
It has been recognized within the Bassetlaw district that a number of facilities are available for people affected by autism who require specialist support. However, very few residents are from the Nottinghamshire area, with the majority of placements being taken up by residents from other Local Authority areas.

Pathway
Clinical support is the main area that would considerably improve the pathway, and associated services for people with autism in the future. The ability to provide services in a single location, and thereby give a single point of access across Psychology, Occupational Therapy and Speech and Language Therapy alongside social care is viewed as the gold standard.

This type of service is already available in Bristol at Bristol Autism Support. The aim of the team is to have joined up working so that service users are not passed around the systems that otherwise exists as people don't necessarily receive a positive outcome in those instances. They aim to work more closely with children in the development of their Education & Healthcare Plans (EHC). In addition, whilst arrangements are already in place, they will give more emphasis to the transition stage to enable young people to have adult services determined at the earliest point possible with sufficient levels of input from the service users and/or carers.

Service User Views

Nottinghamshire Learning Disability and Autism Partnership Board
The Partnership board brings together local service users and carers with personnel from the Local Authority and external agencies to discuss and put forward resolutions to issues affecting people with learning disabilities and/or autism. Recent issues raised include access to specialist dentistry, paying for care, cost of transport and the need for consultation information to be sent out in an easy read format.

Focus Group
A group of service users and carers connected to the Local Authority have been consulted on their views around the main issues affecting them. One of the primary issues was around the difficulty of achieving a diagnosis and the issues that then stemmed from this such as a lack of tailored support within an educational setting and being able to access additional services when required. Once a diagnosis had been received the group felt that there should be some support to assist with both the presenting needs and the psychological aspects of being provided with such a diagnosis, however there was often a sense of relief once diagnosis had been received. Often diagnosis was made when others were being assessed, for example one parent was diagnosed when her son was; and a carer reported that her husband accepted he may also have autism when their son received his diagnosis.

Additionally, the group felt that there was a lack of knowledge and understanding by a range of professionals with regards to their presenting needs (including physical needs). The group felt that professionals often did not understand autism, for example one gentleman was referred for cognitive behavioural therapy and was asked by the psychologist to read a clinical handbook of autism and summarise the points to him. Other experiences included a lack of awareness within services pertinent to women's health such as maternity services and postnatal support for looking after children. The group felt that all professionals should either have some training on autism or have a specialist who is able to support them, for example

one person cited that his physical health is impacted upon by his autism but that this was not recognised when his placement at a support service paid for via a direct payment was removed due to his lack of attendance. The group also felt that hospital staff should receive autism awareness training as there is often a need to do things differently for people with autism i.e. reducing waiting time to keep anxieties to a minimum.

Concerns were also raised around the lack of support with regards to applying for welfare benefits as the people who are able to assist with form completion again lack the detailed knowledge of the presentation of autism. This in turn can affect other aspects of a person's life goals, for example employment support advisors are unavailable unless a person is in receipt of employment support allowance.

Some of the issues reported were more social in nature such as having being bullied whilst at school as people didn't understand their difference, being misdiagnosed as having behavioural problems or being labelled "odd" as an adult. One woman with Asperger's had an autistic son and whilst she found social situations challenging her son enjoys being out and meeting new people. She suggested that help with her guilt and mechanisms to assist her to care for her son in the way she would choose would be beneficial to her. The group thought that establishing social groups may be a way to assist with some of these issues.

The group did provide positive experiences of accessing daytime activities and stated that they had enjoyed doing so as they felt accepted and included as their chosen placements had specialist knowledge of autism. The group felt that whilst there might be services out there suitable for them they were difficult to find and people felt that they were somewhat left to help themselves when sometimes they needed assistance. The group suggested that somewhere they could go to speak to someone face-to-face similar to the services offered for families with children would be a place they could receive this support.

What does this tell us?

8. Unmet needs and service gaps

As part of the Autism Self-Assessment Framework (SAF) a number of actions have been identified which will significantly impact in a positive manner on the lives of people living with autism.

Table 6: Unmet needs and service gaps

Comments taken from the Autism Self-Assessment Framework are in italics

Pathway step	Unmet need/service gap
Training for staff providing services to people with autism	*NCC training is monitored. Is NHS training monitored?* *Hospital training is not mandatory* *There is no co-ordinated system of evaluation.*
Identification and diagnosis of autism in children and adults leading to assessment of needs	*See NICE ASD Local care pathway* *Improved referral route – how do GPs record stats?* *Introduce central system for recording diagnosis to better service the requirements of planning and commissioning services*

Pathway step	Unmet need/service gap
	Different routes to diagnosis – introduce integrated pathway with separate routes for LD/non LD
Planning for transition services	*More support needed for individuals, parents & carers when moving from Children's to Adult Services*
Local provision of services for children and adults	*No psychology service in County* *Limited access to SLT and OT service due to current outpatients systems* *Crisis services to meet needs of people with autism* *DC's are looking at meeting autism needs in housing strategies with trained staff*
Reasonable adjustments and equality	*Meet the needs of older people/women/BME e.g. bespoke training*
Supporting people with complex needs who may display challenging behaviour	The transforming Care Partnership Programme is currently addressing the needs of such people
Employment for adults with autism	*Build employer capacity and support for people with Autism Spectrum Disorders (ASD) and their families, voluntary opportunities? Support at transition?*
Working with the Criminal Justice System	*Training for custody suite officers and Probation Service – e-learning shared?*

9. Knowledge gaps

Knowledge about autism is growing however there are some significant knowledge gaps, for example:

- Lack of systematic recording of people known to services who have an autism diagnosis e.g. from GPs re numbers presenting and diagnoses given
- Lack of consistent collection of data particularly relating to protected communities and age groups in particular minority ethnic and cultural groups, women and older people.
- Lack of data relating to training, its uptake and effectiveness
- Little information regarding the needs of older people, specifically those in residential/nursing care.
- Lack of information from the Criminal Justice Service on their recognition and approach to dealing with people with autism

What should we do next?

10. Recommendations for consideration by commissioners

	Recommendation	Responsibility
Strategic		
1	Create a multi-agency task and finish group for autism as per the Statutory Guidance[46] with assistance from the Health and Wellbeing Board as representatives of key partner organisations (i.e. assistance with identifying and gaining commitment from various stakeholders). The group will ensure the facilitation of a co-ordinated response and enable learning from good practice already available in some areas. As such it will be responsible for writing a local Autism Strategy and developing and implementing an Autism Action Plan based on the findings of this JSNA and the Self Assessment Framework (SAF). The Action Plan will fulfil a SAF target for 2019. The Health and Wellbeing Board will approve the Strategy and Action Plan in line with the Nottinghamshire Health and Wellbeing Board Joint Health and Wellbeing Strategy 2018-2022 priorities for Healthy and Sustainable Places[47]. Responsibility for delivery against the Action Plan and Strategy will lie with the Mental Health, Autistic Spectrum Disorders and Learning Disabilities Integrated Steering Group.	The Mental Health, Autistic Spectrum Disorders and Learning Disabilities Integrated Steering Group with approval from the Health and Wellbeing Board
Health and Wellbeing promotion		
2	Identify specific needs around protected characteristics particularly older people, people from minority ethnic and cultural groups and women, from diagnosis to services available to ensure equality of access. Further research will ensure that services are appropriate for these groups and facilitate their engagement	All public sector agencies alongside voluntary and community sectors
3	At transitions stage build employer capacity and support and resources for people with ASD and their families. Increase the ability of young people to gain the skills they might need to gain employment and reduce the costs of unemployment	Adult Social Care Department, Local Authority
4	Work with local businesses and organisations to maximise employment opportunities for people with autism (not just those at transition) to maximise economic and individual wellbeing across all ages.	Place Department, Local Authority working in partnership with D2N2

[46] Department of Health, Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, March 2015, page 30

[47] Nottinghamshire Health and Wellbeing Board Joint Health and Wellbeing Strategy 2018-2022, page 4

	Recommendation	Responsibility
5	Build community capacity and community responsibility to support people with Autism. Look at modifications to existing services to make them more accessible	Local Authority
Service Delivery		
6	Provision of appropriate training for staff and volunteers working both specifically and more generally with local people within Nottinghamshire. This will enable more systematic availability of services and knowledge of personnel within these services	Nottinghamshire County Council, NHS Commissioner and Provider agencies, voluntary and independent sectors
7	Monitor and evaluate training within all agencies including Experts by Experience training – to enable all agencies to understand how best they might meet the needs of autistic people, as well as knowledge around their own staff groups	Nottinghamshire County Council, NHS Commissioner and Providers agencies, voluntary and independent sectors
8	Investigate how diagnostics and the autism pathway could be improved (including post-diagnostic support). A formal pathway is currently not available and would greatly enhance the lives of those with autism particularly where early intervention services can be put in place	Clinical Commissioning Groups
9	Local audit of poor take up of primary care services and overuse of acute services by those affected by autism.	NHS bodies and NHS Foundation Trusts
10	Address the medical and lifestyle issues which result in poorer health outcomes and increased mortality	NHS and Local Authority Commissioners
Data		
11	Set up and improve data collection across agencies around autism e.g. GPs. This will enable all agencies to gain a true picture of how services are operating and where gaps might exist	NHS Commissioner and Provider agencies and Nottinghamshire County Council

Key contact:
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Strategic Commissioning
ASCH

Useful Links

National Autistic Society
Research Autism
NICE Guidance for Autism
SCIE: Barriers to services for people with autism
SCIE: Transition from children's to adult services for people with autism
NCC Help for people with Asperger's Syndrome

Think Autism 2014
British Psychological Society
College of Occupational Therapists
Research Autism
Royal College of General Practitioners
Royal College of Nursing
Royal College of Paediatrics and Child Health
Royal College of Psychiatrists
Treating Autism
www.autism-connect.org.uk

Appendix 1 Autism Self-Assessment Framework (SAF)