



Norfolk County Council

Needs assessment for adults
and children with autism in
Norfolk

March 2019

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Version 1.9



Contents

Abbreviations	4
Acknowledgements	5
Definitions	6
A note on the figures	8
A note on the text	8
1. Executive Summary	9
1.1 Introduction	9
1.2 Aims	9
1.3 Scope	10
1.4 Key Findings	11
1.4.1 Review of local and national data on autism (Epidemiological Needs Assessment)	11
1.4.3 Experiences of other local areas of the UK (Comparative Needs Assessment)	12
1.5 Recommendations	13
2. Introduction	14
2.1. Background	14
2.1.1 Autism	14
2.1.2 Risk factors for autism	15
2.1.3 Co-morbidities	15
2.1.4 NICE Guidance on supporting people with autism	16
2.1.5 Barriers to accessing support for people with autism	17
2.2 Aims	17
2.3 Objectives	18
Objectives will be met using local and national data on people with autism and their health, social and educational needs. These data will be used to work with others to produce recommendations for the implications for Norfolk County Council in terms of its statutory responsibilities and how to deliver these in partnership, thereby improving outcomes for people with autism.	19
3.1 National policy context	19
4. Methods	22
4.1 Types of needs assessment	22
4.1.1 Epidemiological needs assessment	22
4.1.2 Corporate needs assessment	22
4.1.3 Comparative needs assessment	22
4.2 Study population	23



4.3 Data sources	23
4.3.1 National survey data	23
4.3.3 Local sources of data.....	24
5. Review of local and national data on autism health needs (Epidemiological Needs Assessment)	25
5.1 Summary of local and national data on autism health needs	
5.2 Person – autism prevalence and characteristics	27
5.2.1 Adults (18-64)	27
5.2.2 Older adults	27
5.2.3 Children.....	28
5.2.5 Young people transitioning to adult services	29
5.2.6 Education and employment	30
5.2.7 People with autism in the criminal justice system (CJS).....	33
5.2.8 Co-morbidities and associated health needs.....	34
5.2.9 Housing and social care needs	39
5.3 Place.....	42
5.3.1 Adults (age 16-64) by district.....	42
5.3.2 Older adults by district	42
5.3.3 By CCG	43
5.4 Time	44
5.5 Health inequalities	44
5.5.1 Inequalities between those with autism and the general population	45
5.5.2 Healthcare outcomes.....	45
5.5.3 Access to services for vulnerable groups.....	46
5.5.4 Socioeconomic status.....	46
5.5.5 Children in Need, Looked after children and child protection plans	47
5.5.6 Gender	48
5.6 Data gaps.....	48
5.6.1 Local gaps.....	48
5.6.2 National gaps	49
7. Experience of other areas (Comparative Needs Assessment).....	50
7.1 Summary of experiences in other areas	
7.2 Key gaps in service provision	50
7.3 Learning from other service models	51
8. Relevant services and third sector organisations (up to date as of April 2018).....	51



Norfolk County Council

8.1 Diagnostic services	51
8.2 Specialist Education Services	52
8.3 Acute liaison services	52
8.4 Community Dental Service for People with Learning Disabilities	53
8.4 Voluntary and third sector services.....	53
8.5.1 Autism Anglia	53
8.5.2 National Autistic Society (NAS).....	53
9. References.....	54



Abbreviations

ASC = Autism Spectrum Conditions

ASD = Autistic Spectrum Disorder

CAMHS = Child and Adolescent Mental Health Services

CCG = Clinical Commissioning Group

CiN = Child in Need

CJS = Criminal Justice System

GP = General Practitioner

EHCP = Education Health and Care Plan

HNA = Health Needs Assessment

ICD = International Classification of Diseases

IQ = Intelligence Quotient

JSNA = Joint Strategic Needs Assessment

LA = Local Authority

NCC = Norfolk County Council

NICE = National Institute for Health and Care Excellence

NHS = National Health Service

PANSI = Projecting Adult Needs and Service Information

POPPI = Projecting Older People Population Information

QOF = Quality and Outcomes Framework

UK = United Kingdom



Acknowledgements

We would like to thank members of the Autism Partnership Board who gave their input into this work. In particular we would like to thank Clare Smith for her detailed feedback on this report. We would like to thank Tim Winters, Ben Foster and Jeremy Bone for their advice and assistance on data sources. We would like to thank Frank Crowdy, Transition Lead, for his assistance in identifying data relating to young people transitioning to adult services. We would also like to thank Tracey Walton, Autism Commissioning Manager and Maxine Blocksidge, Senior Advisor SEND for their feedback on the draft report. We would like to thank Zandrea Steward for overseeing this needs assessment in the earlier stages of its development.



Definitions

Autistic spectrum disorder (ASD): This is the term used in the most up to date version of the International Classification of Diseases (ICD-11, see below for definition). According to ICD-11 ASD is “characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive and inflexible patterns of behaviour and interests. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important area of functioning and are usually a pervasive features of the individual’s functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities.” (ICD-11, 2018)



Autism spectrum conditions (ASC): Used by some as an alternative to ASD.

Some consider ASC the appropriate term to refer to an autistic person over the life course, reflecting the fact that they will have autism throughout life but only at certain times will this impact them and they may consider it to be a disorder (Baron-Cohen 2017). Whether ASC or ASD is used generally depends on the diagnostic manual or tool being used.

Autism: Autism is a term often used as a shorthand for what others refer to as ASD or ASC (Baron-Cohen 2017). It is also preferred by some in the autism community as it is seen as less medicalised terminology.

Asperger syndrome: Refers to a group of people with autism who have average or above average intelligence, have fewer problems with speech than many others with autism and who generally do not have a learning disability (National Autistic Society, 2016). There is not a clear boundary between Asperger syndrome and other kinds of autism. The term is no longer included in the ICD as of version 11, but many people identify with this term.

Care pathway: “A system designed to improve the overall quality of healthcare by standardising the care process and promoting organised efficient service user care based on best evidence to optimise service user outcomes.” (NICE 2016)

Education, Health and Care (EHC) Plans: A legal document describing a child or young person’s special educational, health and social care needs and how these will be met through extra help and support (Contact 2012).

Learning disability: A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life (Mencap 2018). A learning disability can range from mild, perhaps meaning a person will need support in gaining employment but be otherwise independent, through to profound and multiple learning disability (PMLD) where a person has multiple disabilities, the most significant of which is a learning disability, and will generally need a carer or carers to help them with most aspects of daily life, such as washing, eating and using the



bathroom (NHS Choices 2015). Some people with autism also have a learning disability, but autism is not a learning disability.

(Specific) Learning difficulty: Specific Learning Difficulties (SLD) affect the way information is learned and processed. Unlike learning disabilities, learning difficulties are not related to intelligence. Examples include dyslexia, dyscalculia, dyspraxia and attention deficit hyperactivity disorder (ADHD) (British Dyslexia Association 2018). SLD can occur alongside autism.

Special Educational Needs (SEN): “a learning difficulty or disability which calls for special education provision to be made” (Children and Families Act 2014) Special educational needs and disabilities (SEND) can affect a child or young person’s ability to learn; their behaviour or ability to socialise, for example they may struggle to make friends; reading and writing, for example because they have dyslexia; ability to understand things; concentration levels, for example because they have ADHD; or physical ability (HM Government 2018).

A note on the figures

Please note that data from several different sources are quoted in this report. These data sources often use different parameters (such as age cut offs and geographical areas). As a result, many of the tables are not comparing like with like and so numbers may not match up as you might expect them to. It is hoped that in the future it will be possible to overcome these data limitations, but for now this is the data we have to work with.

A note on the text

The report is structured as is typical for a Health Needs Assessment in Public Health. The Harvard style of referencing has been used, and as is convention, references are not included within the Executive Summary but are provided within the body of the report.



We are aware that different people have different views on terminology. Throughout this document we have tried to use the term 'autism' as an umbrella term for all autistic spectrum conditions and disorders, including Asperger Syndrome. We use the term 'people with autism', as this is used in the national guidance, but are aware some people prefer the term 'autistic people'. We have used these terms for convenience and consistency and because they are those used in national guidance. We recognise these are not necessarily the terms everyone would choose and want to be clear that this document is intended to be inclusive all those identifying with any of these terms, or related terms.

1. Executive Summary

1.1 Introduction

Autism is a pervasive developmental disorder characterised by differences in social interaction, communication and social imagination. Approximately 1% (rounded to the nearest whole number) of the population are affected. Autism is neither a mental health condition, nor a learning disability, although many people with autism also have one of these conditions.

1.2 Aims

The aim of this work is to provide as comprehensive an assessment as possible of the characteristics and health needs of people of all ages with an autism in Norfolk. This will draw on all reasonably accessible data sources and aims to include both those people eligible for specialist autism services and those who are not, and people with



or without comorbidities. The results will be used to inform the developing local autism strategy, supporting the improvement of outcomes for people with autism.

1.3 Scope

This work reviews health and support needs and provision of services for people with autism of all ages in Norfolk, including those eligible for specialist services and accessibility of universal services for those anywhere on the autism spectrum. This report sets out to identify:

1. Estimates of the numbers of people in Norfolk living with autism, including:
 - a. Those with or without a formal diagnosis;
 - b. Those who have co-morbidities e.g. epilepsy, learning disabilities;
 - c. Those eligible or not eligible for specialist services;
 - d. The geographical spread of people living with autism;
 - e. Trends over time.
2. Estimates of the number of older people living with autistic spectrum disorder who may require tailored health and care services as they age to support future service planning for this group.
3. Descriptions of the health, social and educational needs of people with autism in Norfolk.
4. Identification of existing national and local data sources for autism and assess their comprehensiveness, data quality and usefulness for predicting health needs.
5. Identification of gaps in service provision.
6. Recommendations for the implications for Norfolk County Council in terms of its statutory responsibilities and how to deliver these in partnership, thereby improving outcomes for people with autism.

Objectives will be met using local and national data on people with autism and their health, social and educational needs. These data will be used to work with others to produce recommendations for the implications for Norfolk County Council in terms of its statutory responsibilities and how to deliver these in partnership, thereby improving outcomes for people with autism.



1.4 Key Findings

1.4.1 Review of local and national data on autism (Epidemiological Needs Assessment)

- There were an estimated 5080 adults (aged 16-64) with autism in Norfolk in 2017, projected to rise slightly up to 5211 by 2035 (PANSI 2016).
- There were an estimated 2039 older adults (aged 65+) with autism in Norfolk in 2017, projected to rise considerably to 2826 by 2035 (POPPI 2016).
- There were an estimated 2491 children and young people (aged 0-19) with autism in Norfolk in 2016 (ONS 2017; Baird et al. 2006).
- There were an estimated 9709 people of all ages with autism in 2016 (ONS 2017) (please note this figure does not match exactly with those stated above as the above estimates totalled would lead to double counting of 16-19 years olds, and because it is based on a different method of estimating the number of people with autism).
- An estimated 40% of people with autism may also have a mental health problem (Ghaziuddin et al. 2002)¹.
- An estimated 55% of people with autism may also have a learning disability (Baird et al. 2006)²
- Gathering data on the numbers and needs of people with autism was challenging, as many services know only a small number of local people with autism and many are undiagnosed. Those on the spectrum most likely to be undiagnosed are those without a learning disability. Therefore estimates must be made using population estimates and prevalence estimates from the research literature, and it is unclear how many of these people living in Norfolk have a diagnosis.
- It is likely that many of the adults in Norfolk with autism have not been formally diagnosed, as none of those identified in the Adult Psychiatric Morbidity Survey, a population-based survey, were previously aware that they had autism (Burgha et al. 2011). In particular, it is thought women and girls are less likely to receive a diagnosis, as autism may present differently from men and boys, in whom autism is more common.



- In July 2017 NICE proposed a new set of QOF indicators for potential inclusion in the NICE indicator menu for general practice, one of which was “Autism: The practice establishes and maintains a register of all patients with a diagnosis of Autism” (NICE 2017). This would likely significantly improve the collection of data on adults with autism, bringing this in line with the data on children collected through the Public Health Outcomes Framework (PHOF) indicator ‘Children with autism known to schools’, but both would still miss undiagnosed cases of autism or those not accessing GP or education services. This includes some vulnerable minorities, such as the homeless or traveller communities, causing a potential health inequality. It may also include the large number of people with autism who do not have a learning disability and whose autism is not at present having a negative impact on their
1. Please note this reference was used as it is the most up to date and comprehensive source we were able to identify
 2. This reference was used as it is from the most recent UK based prevalence estimate. A review of the literature by Emerson and Baines reported an average of the prevalence of learning disabilities across studies conducted in the UK, Finland, USA and Iceland between 2000 and 2008 and estimated 52.6% of people with autism may also have LD.

conducted, and key points from assessments from York, Haringey and Swindon identified and summarised.

- Community and voluntary organisations play an important role in providing support for people with autism.
- Many areas have identified gaps in provision of preventative services, to avoid the need for escalation to specialist services or to prevent escalation of behavioural issues.
- Many areas have highlighted a gap in services for people with autism who do not have a co-morbid learning disability or mental health problem and so are not eligible for these services.
- Those with autism and a mental health problem may not access services as often as the general population with mental health problems, leading to health inequalities.
- There is a need for improved access to both universal and focussed services for people with autism by increasing awareness and training about autism among service providers so they can identify people with autism, make



reasonable adjustments and provide services meeting the needs of people with autism.

1.5 Recommendations

- Use this document in conjunction with the All Age Autism Strategy for Norfolk to include action on these recommendations as well as the national strategy and statutory guidance to improve the lives of people affected by autism.
- Support the Norfolk Autism Partnership Board (NAPB) and an associated Autism Partnership Group (NAPG) in the implementation of the Norfolk Autism Strategy. The Board includes experts by experience and partners from agencies involved in supporting people with autism.
- Providing the right support for people with autism at the right time – including those transitioning from children’s to adult’s services, and from adult services to older people’s service.
- Collaborate with voluntary and third sector organisations, particularly to support provision of lower level preventative and support services to support involvement of people with autism in their communities.
- **Training:** Support the NAPB training working group to make autism awareness training available to all staff in services working with people with autism whose decisions have a significant impact and whose career paths bring them into contact with people with autism and their families. An e-learning package has been developed for this purpose.
- **Diagnostic pathways:**
 - Ensure local autism care pathways are available, suitable and equitable for all age groups and geographical locations across Norfolk, working in collaboration with the NAPB. The Diagnostic Working Group of the NAPB may wish to consider whether a Single Point of Contact for people seeking to use the autism diagnostic pathway would contribute to these ambitions.
 - Pathways should be accompanied by: clear policy and protocols for the operation of the pathway; multi-agency training about autism and the



pathway; raising awareness of the pathway and how to access services among relevant professions; support smooth transitions between services for people with autism at different times in their lives (e.g. children's to adult services); audit and review of the pathway.

- Data from this report suggests it is likely that many of the adults in Norfolk with autism have not been formally diagnosed, so there is a particular need for diagnostic services for this group.
- Support the NAPB data working group to improve the collection of local data on autism.

2. Introduction

2.1. Background

2.1.1 Autism

According to ICD-11 Autistic Spectrum Disorder is “characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive and inflexible patterns of



behaviour and interests. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important area of functioning and are usually a pervasive features of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities." (ICD-11, 2018). A prevalence of 1% in the population is generally quoted in the literature. Prevalence has increased in recent years, although this is thought to be due to improved awareness and recognition, changes in diagnosis and younger age of diagnosis (Lai et al. 2014).

Autism exists on a spectrum, so while all people with autism share certain underlying difficulties, autism affects people in different ways, to different degrees and in different ways at different times in their lives (Lai et al. 2014).

Autism is more commonly diagnosed in men and boys, although the magnitude of the difference is debated. Large-scale population studies have suggested autism is 2-3 times more common in men and boys than in women and girls, although autism in women and girls is thought to be under-recognised, perhaps due to differences in presenting signs and symptoms and diagnostic gender bias (Lai et al 2014).

2.1.2 Risk factors for autism

A variety of genetic and environmental risk factors for autism have been identified but none which have been shown to be necessary or sufficient for autism to develop (Lai et al 2014).

2.1.2.1 *No association with MMR*

There is no evidence that the MMR (measles, mumps, and rubella) vaccine causes autism (Lai et al. 2014).

2.1.3 Co-morbidities



Over 70% of people with autism have another condition of some kind. Common co-occurring conditions are outlined in the table below.

Condition	% of people with autism effected
Developmental	
Learning disability	45%
ADHD	28-44%
Tic disorders	14-38%
Motor abnormality	<79%
General medical	
Epilepsy	8-30%
Gastrointestinal problems (e.g. chronic constipation, chronic diarrhoea, abdominal pain, reflux)	9-70%
Genetic syndromes (e.g. fragile X syndrome, Rett syndrome)	5%
Sleep disorders (e.g. insomnia)	50-80%
Psychiatric	
Anxiety	42-56%
Depression	12-70%
Obsessive-compulsive disorder	7-24%
Psychotic disorders e.g. schizophrenia	12-17%
Substance misuse	<16%
Oppositional defiant disorder	16-28%
Eating disorders	4-5%
Personality disorders	
Paranoid personality disorder	0-19%
Schizoid personality disorder	21-26%
Schizotypal personality disorder	2-13%
Borderline personality disorder	0-9%
Obsessive-compulsive personality disorder	19-32%
Avoidant personality disorder	13-25%
Behavioural	
Aggressive behaviours	<68%
Self-injurious behaviours	<50%
Pica	36%
Suicidal ideation or attempt	11-14%

Table 1 - Commonly occurring co-morbidities among people with autism (Lai et al. 2014)

2.1.4 NICE Guidance on supporting people with autism

The National Institute for Health and Care Excellence has produced several pieces of guidance on autism:

- Autism spectrum disorder in adults: diagnosis and management (NICE 2016)



- Autism spectrum disorder in under 19s: support and management (August 2013)

This guidance includes key principles for working with people with autism and their families, including working in partnership with them, offering support and care respectfully and taking time to build trusting relationships. The guidance emphasises the need for staff to have adequate training and understanding of autism and how it might affect a person's life and day-to-day functioning. Professionals should encourage autonomy and self-management, ensure information is provided in a way that is understandable (e.g. easy read) and take into account the physical environment in which care is provided. There should be a local autism multi-agency strategy group involving representatives from local services and people with autism. Families, partners and carers should be involved if the person with autism wants them to be, and in a way which suits them.

2.1.5 Barriers to accessing support for people with autism

As a spectrum of conditions, the needs of people are very varied (Alabady et al. 2013). Diagnostic services are limited and often have long waiting lists. Autism, while associated with greater risk of mental illness, is not a mental illness, and so mental health services generally only provide support to people with autism who also have significant mental health comorbidities. People with autism are at greater risk of having a learning disability, but many people with autism do not have a comorbid learning disability. Learning disability services generally focus on those with a learning disability. This leaves a gap in services, particularly for those with Asperger Syndrome, who generally have neither a mental health condition nor a learning disability, and are typically unable to access an appropriate range of support from health and social care services.

Challenges to accessing universal services may also be present due to a lack of autism training and awareness among service providers (Alabady et al 2013).

2.2 Aims



The aim of this work is to provide as comprehensive an assessment as possible of the characteristics and health needs of people of all ages with autism in Norfolk. This will draw on all reasonably accessible data sources and aims to include both those people eligible for specialist autism services and those who are not, and people with or without comorbidities. The results will be used to inform the developing local autism strategy, supporting the improvement of outcomes for people with autism.

2.3 Objectives

The specific objectives are:

1. Estimates of the numbers of people in Norfolk living with autism, including:
 - a. Those with or without a formal diagnosis;
 - b. Those who have co-morbidities e.g. learning disabilities;
 - c. Those eligible or not eligible for specialist services;
 - d. The geographical spread of people living with autism;
 - e. Trends over time.
2. Estimates of the number of older people living with autistic spectrum disorder who may require tailored health and care services as they age to support future services for this group.
3. Descriptions of the health, social and educational needs of people with autism in Norfolk.
4. Identification of existing national and local data sources for autism and assessment of their comprehensiveness, data quality and usefulness for predicting health needs.
5. Identification of gaps in service provision.
6. Recommendations for the implications for Norfolk County Council in terms of its statutory responsibilities and how to deliver these in partnership, thereby improving outcomes for people with autism.



Objectives will be met using local and national data on people with autism and their health, social and educational needs. These data will be used to work with others to produce recommendations for the implications for Norfolk County Council in terms of its statutory responsibilities and how to deliver these in partnership, thereby improving outcomes for people with autism.

3.1 National policy context

The Autism Act 2009 placed a duty on the Government to produce a national autism strategy for adults in England, along with statutory guidance for local councils and health bodies on how to implement this. This placed a statutory duty on the NHS and Local Authorities to ensure that services are in place to meet the needs of people with autism.

The first government autism strategy, *Fulfilling and Rewarding Lives* was published in 2010, and the latest strategy, *Think Autism*, was published in April 2014. The latest supporting statutory guidance was published in 2015.

Fulfilling and Rewarding Lives recommendations included:

- Autism awareness training for staff in public, health and social care services, in line with the needs of their job;
- Setting up a local diagnostic pathway based on National Institute for Health and Care Excellence Guidance (NICE) *Clinical guidelines on the recognition, referral, diagnosis and management of adults on the autistic spectrum* published in 2012;
- Increasing capacity around diagnosis;
- Ensuring adults with autism and their carers are provided with information and access to local support on diagnosis;
- Person-centred assessment of an individual's needs following diagnosis;
- Improving access for adults with autism to the support and services they need to live independently in their community;
- A commitment to providing personalised care and support;
- Support for young people transitioning to adulthood;



- Supporting adults with autism into work;
- Learning from service models that have been shown to make a positive difference for people with autism;
- Enabling adults with autism and their families to have choice and control about where they live;
- Involving adults with autism in the development of local services through an Autism Partnership Board (APB) or similar.

Building on this report, *Think Autism* proposed:

- Autism Aware Communities – establishing local community awareness projects and pledges for local organisations to work towards;
- Funding for projects that promote innovative local services, particularly for lower-level preventative support;
- Inclusion of quality autism awareness training within general equality and diversity training programmes across all public services;
- In addition to general autism awareness training for staff, local areas should develop or provide specialist training for those in roles that have a direct impact on access to services for adults with autism;
- Better data collection and information sharing between services.

As well as improving services for people with autism, there is evidence that implementation of the statutory guidance will likely be cost saving. For example, if local services were able to identify and support just 8% of adults with autism without a learning disability, it could save the Government an estimated £67 million per year (The National Autistic Society 2017).

Local authorities are required to report their progress toward improving services for autistic adults regularly through a self-assessment exercise, and it is suggested that areas should have an Autism Partnership Board. Norfolk set up the “Norfolk All Age Autism Partnership Board (NAPB)” in April 2018 in response to this, following the guidance of *Think Autism* and other statutory guidance, which will inform the implementation of the Norfolk Autism Strategy and action plans to deliver the National



Autism Strategy in Norfolk. The Board seeks to be inclusive, ensuring active participation of service users, parents and carers. It seeks to influence NHS and local authority commissioners with the aim of developing improved services for children, young people and adults who have, or who may have, autism, and raise awareness within the wider community to enable people with autism to be fully included in society. The NAPB report to the Health and Wellbeing Board. The wider Norfolk Autism Partnership Group (NAPG) has an informal membership of people who have autism, their families and people who work in relevant fields, enabling the wider community to feed into the work of the APB.

Under the Care act 2014, all adults with eligible needs for care and support are entitled to public care and support, subject to their financial circumstances. Local authorities are required to ensure people who live in their areas receive services that prevent their care needs becoming more serious, can access information and advice to make decisions about their care and have a range of high quality, appropriate services to choose from which support their wellbeing.

The Department for Education (DfE) produced a tool on the Preparing for Adulthood (PfA) outcomes for children and young people with Special Educational Needs and Disabilities (SEND). This this is focused around community inclusion, independent living, preparing young people for employment and promoting health.

Transforming Care is a national initiative developed by the Local Government Association, NHS England and the Association of Directors of Adult Social Services, to develop and transform care plans and choice for users of health and social care services. The national plan *Building the Right Support* was published in 2015 and outlines how community services can be developed to provide an alternative to inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition (NHS England 2015). The Norfolk and Waveney Transforming Care Partnership involves people with learning disabilities and/or autism and their families, commissioners, service providers, voluntary organisations and other statutory stakeholders (Norfolk County Council 2016). They have developed a plan consistent with the national framework, to improve the use of care plans, support people with learning disabilities



to make choices about where they live and facilitate care in the community, rather than hospital, where possible.

4. Methods

4.1 Types of needs assessment

We undertook epidemiological, corporate and comparative needs assessments:

4.1.1 Epidemiological needs assessment

The epidemiological needs assessment aimed to provide a reliable estimate of the number of people of all ages living in Norfolk with autism, and where possible, an indication of the severity of their condition and comorbidities. We also explore the socio-demographic characteristics (age, sex, ethnicity, socioeconomic status) of these people and utilisation of services where possible.

4.1.2 Corporate needs assessment

A corporate needs assessment aims to engage key stakeholders in Norfolk including people with autism, their families and carers, people working with those with autism and relevant voluntary/third sector organisations. There has been input into this document from experts by experience and representatives of relevant partner organisations. Further input will be sought through an engagement survey with people with autism and their families after publication of this needs assessment. This will aim to assess whether the issues set out in the national Autism Strategy and the Autism Act are being addressed in Norfolk and identify gaps and priorities. Results will be incorporated into the next update of this document.

4.1.3 Comparative needs assessment

The "comparative approach" to needs assessment compares and contrasts services provided to the population in one geographical area with those received elsewhere.



Through analysing epidemiological data and health needs assessments from other geographical areas we sought to identify gaps in health and community services provision for people living with autism in Norfolk and identify examples of good practice elsewhere. This facilitated learning from service models that have been shown to make a positive difference for people with autism, as recommended in the national Autism Strategy.

4.2 Study population

The HNA reviewed the current health and support needs and provision of services for people with autism of all ages in Norfolk, anywhere on the autistic spectrum.

4.3 Data sources

Routinely available data describing the epidemiology of autism for all ages in Norfolk and the utilization of health services were included.

4.3.1 National survey data

4.3.1.1 *Adult Psychiatric Morbidity Survey 2014*

The Adult Psychiatric Morbidity Survey (APMS) provides an estimate of those living with autism in England (Brugha et al. 2016). The survey involved taking a probability (random) sample of adults (aged 16-64) from different population groups (strata) in households in England and assessing for a range of psychiatric conditions, including autism. The most recent survey was conducted in 2014.

4.3.1.1.1 *Adult Psychiatric Morbidity Survey Methods*

Autism assessment involved screening using the Autism Quotient (AQ-20), followed by assessment for those scoring above a cut of score (AQ score 4 or more) by a trained interviewer using the Autism Diagnostic Observation Schedule (ADOS). This approach has been extensively validated. Due to the limited sample size of people



identified with autism in the survey (n=31), further exploration of the characteristics of this group must be taken with caution. It was not possible to include adults with learning disability in the 2014 survey, but they were included in a 2007 extension of the AMPS (Brugha et al. 2012), and no significant change in autism prevalence in the combined 2014 and 2007 surveys was identified when the population of adults with learning disabilities was accounted for in the analysis.

Similar surveys were completed in 1993 (with adults aged 16 to 64 in England, Scotland and Wales), 2000 (with adults aged 16 to 74 in England, Scotland and Wales) and 2007 (with adults age 16 and above in England), enabling some analysis of combined samples, with the aim of better estimating the prevalence of rarer conditions. Data were combined from 2007 and 2014 (n=7,500) to generate a larger sample size for autism analyses.

4.3.1.2 Large-scale surveys from the research literature estimating the prevalence of childhood autism

These were used to extrapolate and make estimates of autism prevalence in Norfolk, taking into consideration the demographic profile of the local population where possible.

4.3.3 Local sources of data

- Children with a statement of Special Educational Needs (SEN);
- Public Health Outcomes Framework data on children with autism known to schools for Norfolk;
- Children on the Norfolk Register of Disabled Children with autism;
- Mental Health Services Data Set (MHSDS 2017).



5. Review of local and national data on autism health needs (Epidemiological Needs Assessment)



5.1 Summary of local and national data on autism health needs

- There were an estimated 5080 adults (aged 16-64) with autism in Norfolk in 2017, projected to rise slightly up to 5211 by 2035 (PANSI 2016).
- There were an estimated 2039 older adults (aged 65+) with autism in Norfolk in 2017, projected to rise considerably to 2826 by the year 2035 (POPPI 2016).
- There were an estimated 2491 children and young people (aged 0-19) with autism in Norfolk in 2016 (ONS 2017; Baird et al. 2006).
- An estimated 40% of people with autism also have a mental health problem (Ghaziuddin et al. 2002).
- An estimated 55% of people with autism also have a learning disability (Baird et al. 2006).
- Gathering data on the numbers and needs of people with autism is challenging, as many services know only a small number of local people with autism and many people are undiagnosed. Estimates must be made by applying rates from the research literature to the Norfolk population. Data may improve if a NICE proposal that autism is recorded in GP records is implemented.
- It is likely that many of the adults in Norfolk with autism have not been formally diagnosed, as none of those identified in the Adult Psychiatric Morbidity Survey were previously aware that they had autism (Burgha et al. 2011).

Establishing how many people in the population have autism is challenging because there is no central database recording this information. People with autism may access a variety of different services or no services, and so no single source of data is adequate (Solihull Metropolitan Borough Council 2012). There are also people living with autism which has never been diagnosed, particularly older people or those who have not sought support.

Epidemiological data will be considered in terms of person (numbers and characteristics of people with autism in Norfolk such as age, sex and comorbidities),



place (where in Norfolk people with autism are living and accessing services) and time (projected changes in autism prevalence in Norfolk over time).

5.2 Person – autism prevalence and characteristics

5.2.1 Adults (18-64)

Most estimates of autism prevalence among adults in England are extrapolations from the Adult Psychiatric Morbidity Survey (APMS) described above. This survey estimated overall autism prevalence in England to be around 0.8% (95% CI 0.5% to 1.3%) (n=31 people with autism identified in the survey). According to the APMS prevalence was higher in men (1.5%, 95% CI 0.8% to 2.6%) than women (0.2%, 95% CI 0.1% to 0.6%). There was some variation seen in autism prevalence by age but there was no clear pattern to this.

Extrapolation of data from the Adult Psychiatric Morbidity Survey 2007 by Projecting Adult Needs and Service Information (PANSI) estimated that there was a total of 5,080 people aged 18-64 living with autism in Norfolk in 2017. This is projected to rise to 5,211 by 2035 (Table 2).

Age group	2017		2020		2025		2030		2035	
	F	M	F	M	F	M	F	M	F	M
18-24	70	664	66	630	65	619	73	691	74	704
25-34	103	954	105	985	102	981	96	927	99	954
35-44	99	871	100	889	108	963	111	1012	108	1008
45-54	124	1084	119	1035	108	940	108	940	116	1013
55-64	117	994	124	1064	134	1145	130	1103	119	1015
18-64	513	4567	515	4603	517	4648	518	4673	516	4694

Table 2 – People with autism by age group for adults (age 16-64) (PANSI 2016)

It is challenging to estimate how many of these adults with autism have been diagnosed, as the range of services they may or may not access is broad, and many services do not routinely collect easily accessible data on whether their users have autism. It is likely that many of the adults in Norfolk with autism have not been formally diagnosed, as none of those diagnosed in the Adult Psychiatric Morbidity Survey were previously aware that they had autism (Burgha et al. 2011).

5.2.2 Older adults



Estimates for older adults (those aged 65 and over) in Norfolk were obtained from the Projecting Older People Population Information System (POPPI 2016) (Table 3).

	2017	2020	2025	2030	2035
65-74	1137	1135	1101	1232	1332
75+	902	1008	1239	1365	1494
Total 65+	2039	2143	2340	2597	2826

Table 3 - People with autism by age group for older adults (65+) (POPPI 2016)

Norfolk’s population is ageing and as a result numbers of older people with autism are projected to rise considerably, from 2039 in the year 2017 to 2826 in the year 2035. This will have particular implications for the provision of social care to older people, as more of them may have specific needs associated with having autism.

5.2.3 Children

5.2.3.1 Estimates from research studies

Baird et al. estimated the prevalence of “autism” in children in the South Thames area as 38.9 per 10,000 (95% CI 29.9 to 47.8) and “other ASD” 77.2 per 10,000 (52.1% to 102.3%), making the total prevalence of “all ASDs” 116.1 per 10,000 (09.4 to 141/8).

Baron-Cohen et al. estimated prevalence of autism-spectrum conditions among school children (diagnosed and previously undiagnosed) in Cambridgeshire (Baron-Cohen et al. 2009). Prevalence estimates based on known cases from a SEN register and a diagnosis survey (where parents reported a child’s diagnosis) were 94 per 10,000 and 99 per 10,000 respectively. When children previously undiagnosed, who received an ASC diagnosis as part of screening and assessment carried out during the study, prevalence was estimated as 157 per 10,000, suggesting a ratio of known to unknown cases of 3:2.

Taylor et al. estimated autism prevalence in the UK among 8 year olds using the UK General Practice Research Database (GPRD) and estimated prevalence as approximately 38 per 10,000 for boys and 8 per 10,000 for girls.



These studies are broadly consistent with the 1% prevalence estimate widely quoted in the research literature (Lai et al.). Estimates from these studies can be used to estimate the prevalence of autism on different parts of the spectrum in Norfolk.

5.2.3.2 Extrapolating from large scale-surveys from the research literature

The numbers of children with “autism” and “ASD” age 0 to 19 were estimated using Norfolk mid-year population estimates for 2016 from the Offices for National Statistics (ONS 2017) and estimates of “autism” and “ASD” prevalence in the population from Baird et al. (2006). As shown in Table 4, there are an estimated 2491 children and young people (age 0-19) with all autism and ASD in Norfolk.

Norfolk and Waveney CCG 2016 ONS resident population estimates	Population 0 to 19	Autism (38.9 per 10,000)	Other ASD prevalence (77.2 per 10,000)	All autism and ASD Prevalence 0-19yrs 116 per 10,000)
Great Yarmouth & Waveney	47,054	183	363	546
North Norfolk	32,884	128	254	381
Norwich	47,097	183	364	546
South	50,948	198	393	590
West Norfolk	36,958	144	285	428
Total	214,941	836	1659	2491

Table 4 - Estimates numbers of children and young people (age 0-19) with autism and ASD in Norfolk by CCG

5.2.5 Young people transitioning to adult services

Based on the estimates in Table 5 above, if all children aged 14-18 were assumed to be transitioning from children’s to adult’s services, there would be approximately 655 young people in the process of transitioning at any one time and approximately 131 young people completing their transition annually. However, as many people with autism do not access services, this figure is likely an overestimate.



5.2.6 Young people who have an Education Health and Care Plan with autism

Data is collected in Norfolk on young people who have an Education Health and Care Plan (EHCP) in which autism is recorded as a primary need or where it is recorded as a secondary need with the primary need being a learning disability.

EHCP's are a good way of tracking the transition cohort and identifying those young people most likely to need Adult Services. However, there are some young people with autism and unmet needs who do not have an EHCP. In particular, those with autism and a mental health problem but no EHCP who will be transitioning to adult services will be missed in these figures.

While these figures are not representative of the general number of young people aged 14-18 with autism, they provide an estimate of the numbers of young people likely to need adult services. This is likely to be an underestimate because not all those young people who need support have an EHCP, and some of those with autism do not receive a diagnosis until adulthood.

The data are divided into those most likely to need services, generally those with autism and a learning disability with severely restricted daily functioning (described as "alerts"), and those who may need a service but generally live quite independently (termed "awares"). Numbers are based on the year in which they reach 18 (Table).

Year	Alerts	Awares	Total
2017	23	23	46
2018	49	41	90
2019	44	39	83
2020	46	24	70

5.2.6 Education and employment

5.2.6.1 Adults

According to APMS, in which the sample size was small and so caution must be taken, autism was inversely associated with level of educational qualification, with autism prevalence higher among those with no qualifications (Figure 1).



Base: all adults

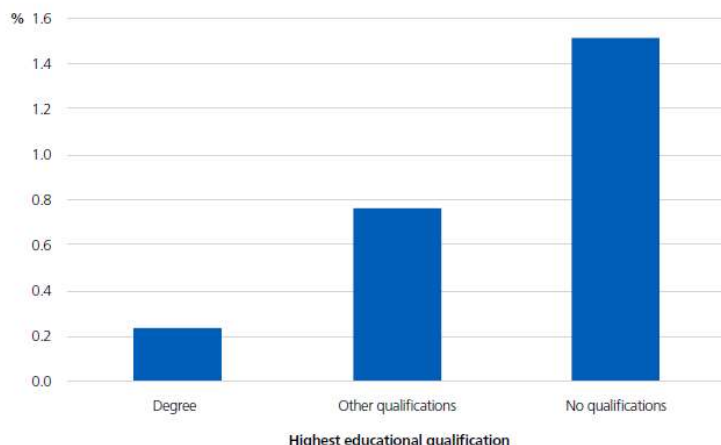


Figure 1 - Highest educational qualification, for people identified with autism as part of the APMS (2007 and 2014 survey data combined)

Employment status was not significantly associated with autism diagnosis, however, this is a topic which the APMS authors acknowledge is complex and needs more detailed study than was possible with their sample size of 31.

5.2.6.2 Children

5.2.6.2.1 Children with a statement of Special Educational Needs (SEN)

Table 6 displays the number of children with Special Educational Needs whose primary need is recorded as autism in different educational settings in Norfolk, compared with the East of England and England. This illustrates that most children and young people with SEN and autism as their primary type of need are in mainstream schools.

	Primary Schools			Secondary Schools			Special Schools		
	Norfolk	East of England	England	Norfolk	East of England	England	Norfolk	East of England	England
Autism	627	5002	42494	480	4130	35706	293	2433	30203
Total SEN	9711	65616	633104	6183	45749	399066	1291	11199	112114

Table 5 - Numbers of children with SEN in state-funded schools whose primary type of need is recorded as autism, by setting (Department for Education 2017)



Autism is listed as the Primary Need for 6% of children with Special Educational Needs (SEN) in state-funded Primary Schools, 7% in Secondary Schools and 22% in Special Schools, in Norfolk (Norfolk County Council 2017).

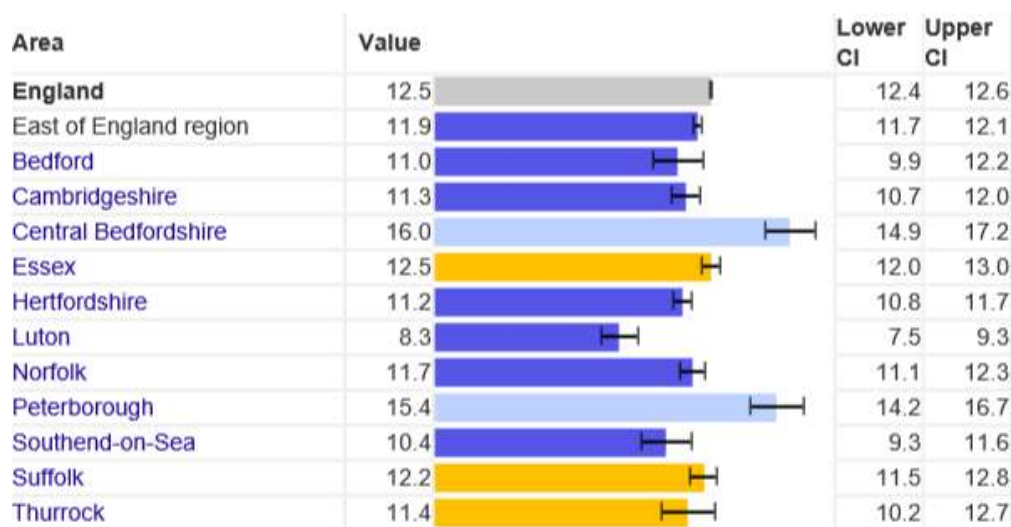
5.2.6.2.2 Children with autism known to schools

Table 7 illustrates that approximately 11.7 children per 1000 are known to schools with autism (n=1400). This is slightly below the regional and England average (Figure 2) and is broadly in line with estimates from the research literature (Baird et al. 2006, Baron-Cohen et al. 2009).

Numbers of children known to schools with autism have been increasing since at least January 2008, when just below 6 per 1000 children living in Norfolk were known to schools as having autism (absolute number of children = 709). The trend is similar in the East of England and England as a whole, and is thought likely due to increased awareness of the condition.

	Norfolk		Region	England	Lowest in England	Highest in England
	Count	Per 1000	Per 1000	Per 1000	Per 1000	Per 1000
Children with autism known to schools (2017)	1400	11.7	11.9	12.5	5.0	27.7

Table 6 - Children with autism known to schools (PHE Fingertips 2017)



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

Figure 2 - Children with autism known to schools in Norfolk compared with the East of England region and England (Department for Education)

5.2.7 People with autism in the criminal justice system (CJS)

People with autism may have contact with the criminal justice system (CJS), including the police, youth offending service, courts, prisons or probation service as a victim, witness or offender, or as a family member of one of these groups.

There is some literature suggesting that people with autism are overrepresented in the CJS (Cashin and Newman 2009) and some suggesting they are not (King and Murphy 2014) but the evidence is limited and uses a variety of methodologies, making comparison difficult. An online survey of experiences of people with autism who had been involved with the CJS were largely dissatisfied with their experience and the lack of trained police officers (Crane et al 2016). Only 42% of police officers surveyed were satisfied with how they had worked with people with autism, with organisational and time constraints, lack of access to training and lack of tailored policing roles identified as barriers.

People with autism may face additional challenges when interacting with the CJS if their needs and potential different ways of thinking are not understood, and may find the loud and restrictive environments of police stations and prisons particularly challenging.



No easily accessible data are available on numbers of people with autism in the CJS locally.

5.2.8 Co-morbidities and associated health needs

5.2.8.1 *Mental health*

People with autism are thought to be at greater risk of mental illness than the general population, although it is hard to separate vulnerability to mental illness due to autism specifically from vulnerability to mental illness due to learning disabilities more generally.

A literature review by Lai et al. (2014) compiled estimates of the proportion of people with autism effected by a range of different conditions from the research literature. Those relating to mental health conditions have been applied to Norfolk population estimates, to estimate the number of people with autism in Norfolk who also have various mental health conditions (Table 8).



Condition	% of people with autism effected	Estimated number in Norfolk
Total people with autism in Norfolk	100%	9709*
Psychiatric comorbidities		
Anxiety	42-56%	4078 to 5437
Depression	12-70%	1165 to 6796
Obsessive-compulsive disorder	7-24%	680 to 2330
Psychotic disorders e.g. schizophrenia	12-17%	1165 to 1651
Substance misuse	<16%	<1553
Oppositional defiant disorder	16-28%	1553 to 2719
Eating disorders	4-5%	388 to 485
Personality disorder comorbidities		
Paranoid personality disorder	0-19%	Up to 1845
Schizoid personality disorder	21-26%	2039 to 2524
Schizotypal personality disorder	2-13%	194 to 1262
Borderline personality disorder	0-9%	Up to 874
Obsessive-compulsive personality disorder	19-32%	1845 to 3107
Avoidant personality disorder	13-25%	1262 to 2427
Behavioural		
Self-injurious behaviours	<50%	Up to 4855
Pica	36%	3495
Suicidal ideation or attempt	11-14%	1068 to 1359

Table 7 - Estimated number of people in Norfolk with autism and specific co-morbid mental illness diagnoses (extrapolated from estimates by Lai et al. 2014)

*Figure based on application of prevalence estimates by age to ONS mid-year population estimates for Norfolk for 2016 (ONS 2017).

Ghaziuddin et al. (2002) suggested 40% of people with autism have a psychiatric comorbidity. In total, this would mean of the estimated 9709 people of all ages with autism in Norfolk, 3884 are likely to have a mental health problem. However, there are many barriers to accessing mental health services for people with autism, including lack of knowledge and competency in supporting people with autism in mainstream services. This means mental health conditions of people with autism are often not recognised or are incorrectly managed (Alabady et al. 2013). People with autism in the APMS were less likely to use services for a mental health reason than



people without autism. This result from a national survey is surprising and concerning given the higher prevalence of mental illness in this group.

5.2.8.2 Learning disabilities

5.2.8.2.1 Extrapolations from national prevalence data

Knapp et al. estimated the numbers of people with autism with or without a learning disability, based on data from Baird et al. (2006) and the assumption that only 10% of children aged 0-3 with autism will have received a diagnosis by that age.

These estimates were extrapolated to Norfolk population figures to estimate the number of people with autism in Norfolk by level of functioning (Table 5).

Age-functioning group		Prevalence per 10,000 population*	People in Norfolk	Estimated number of people with autism in Norfolk
Age 0-3 (Pre-school)	No LD	4.5	42,575	19
	LD	5.5		23
Age 4-11 (Primary school)	No LD	45	87,885	395
	LD	55		483
Age 12-17 (Secondary school)	No LD	45	61,402	276
	LD	55		338
Age 18+ (Adults)	No LD	45	817,522	3679
	LD	55		4496
Total				9709

Table 8 - Level of functioning by age group

*Based on the assumption that only 10% of children aged 0-3 with autism will have received a diagnosis by that age

Other common developmental co-morbidities include ADHD, tic disorders and motor abnormalities. Numbers were estimated based on extrapolating prevalence data from the research literature to the Norfolk population (Table 9).



Condition	% of people with autism effected	Estimated number in Norfolk
Total adults (aged 16-64) with autism	100%	5080*
Developmental co-morbidities		
Learning disability	45-55%	2614 to 2794
ADHD	28-44%	1422 to 2235
Tic disorders	14-38%	711 to 1930
Motor abnormality	<79%	4013

Table 9 - Adults with co-morbid developmental co-morbidities (extrapolated based on prevalence estimates from Lai et al. 2014). *Estimated from PANSI (2016)

5.2.8.2.2.1 Children and young people (aged 1-24) on the Norfolk Register of Disabled Children and Young People

There were a total of 3,222 children and young people aged 1-24 on the Norfolk Register of Disabled Children and Young People as of February 2017 (Norfolk County Council 2017). Registration on this database is voluntary and so this does not represent the total number of children with a disability in the county. Of children on the register 28% are aged <10, 63% aged 11-20 and 8% aged 21-24. Autism is the most commonly recorded 'primary condition' (29% of children on the register, n=932), followed by Attention Deficit Disorder (ADD)/Attention Deficit Hyperactivity Disorder (ADHD) (12% of children on the register) and Global Developmental Delay (GDD) (12% of children on the register) (Table 10). Autism appears to make up a significant proportion of the conditions causing disability among children in Norfolk.



Condition	No. Children on Norfolk CWD Register	% of Register
Autism (including Autism Spectrum Disorder and Asperger Syndrome)	932	29%
ADHD/ADD	386	12%
Global Developmental Delay	384	12%
Sensory Impairment	206	6%
Dyslexia	184	6%
Dyspraxia	164	5%
Epilepsy	139	4%
Cerebral Palsy	136	4%
Profound & Multiple Learning Disab	130	4%
Other Physical Injury/impairment	78	2%
Downs Syndrome	75	2%
Hypermobility	58	2%
Chronic Illness	53	2%
Other	297	9%
Total	3222	100%

Table 10 - Children on the Norfolk Register of Disabled Children by primary condition (Norfolk JSNA Briefing Document 2017)

5.2.8.3 Physical health

Common physical health conditions among people with autism include gastrointestinal problems, sleep disorders and epilepsy (Table 11). Less common, but an important co-morbidity in around 5% of people with autism, are genetic syndromes such as fragile X syndrome or Rett syndrome.



Condition	% of people with autism effected	Estimated number in Norfolk
Total people with autism in Norfolk	100%	9709*
General medical co-morbidities		
Epilepsy	8-30%	777 to 2913
Gastrointestinal problems (e.g. chronic constipation, chronic diarrhoea, abdominal pain, reflux)	9-70%	874 to 6796
Genetic syndromes (e.g. fragile X syndrome, Rett syndrome)	5%	485
Sleep disorders (e.g. insomnia)	50-80%	4855 to 7767

Table 11 - Physical health co-morbidities (extrapolated based on prevalence estimates compiled by Lai et al. 2014). *Figure based on application of prevalence estimates by age from Baird et al. (2006), PANSI (2016) and POPPI (2016) to ONS mid-year population estimates for Norfolk for 2016 (ONS 2017).

5.2.9 Housing and social care needs

5.2.9.1 Housing

Estimates of the numbers of adults, children and young people with autism living in different settings were calculated based on assumptions used by Knapp et al. (2006) in an economic evaluation of the cost impacts of autism. These assumptions, based on prevalence estimates from the research literature in combination with expert communications, were:

- All children with high-functioning autism were assumed to live with their parents in a private household. This assumption was made by Knapp et al. based on the research literature and expert communications but will almost certainly lead to an underestimate as there may be children with high-functioning autism who are looked-after;
- All Children in Need with autism were assumed to be low-functioning. An estimated quarter of children with autism are estimated to be CIN (Bebbington and Beecham 2007). All those low-functioning and not CIN were assumed to be living with a relative in a private household.
- Among adults with autism without LD autism 79% live in private households, 5% Supporting People accommodation and 16% in residential care.
- Among adults with low-functioning autism 31% living in private households with parents or other relatives, 2% in private households alone, 2% in private



households with partner, 7% in Supporting People accommodation, 52% in residential care and 6% in hospital.

Applying these assumptions to estimates of numbers of people with autism in Norfolk described above, it was possible to estimate the numbers of children and adults with autism in each residence category in Norfolk, providing a broad overview of possible housing and social care needs.

	Total	With relative in private household	Children's residential or foster care
Children high-functioning	1121	1121	0
Children low-functioning	1370	747	623

Table 12 - Estimated children with autism in Norfolk by type of residence

	Total	Living in private household	Supporting People Accommodation	Adult's residential care	Hospital
Adults with autism without LD	3679	2906	184	589	0
Adults with autism with LD	4496	1574	315	2338	270

Table 13 - Estimated adults with autism in Norfolk by type of residence

5.2.9.2 Adults with autism known to adult social care and accessing their services

As of April 2018 Norfolk County Council supports 503 adults with autism. Of these, 123 have a condition described within the data collected as "Asperger's Syndrome/High Functioning Autism" and 380 have a condition described as "Autism (excluding Asperger's Syndrome/High Functioning Autism)".

91 of these 503 adults with autism supported by NCC is also recorded as having a Learning Disability and 57 are within a Mental Health cost centre, indicating they receive primarily mental health services.

This data does not include all of those with autism known to adult social services, only those for whom this is recorded. There are some issues with the way in which



the form this data is recorded on is designed and used, particularly in relation to those with autism without a learning disability. On the form, whilst it is possible to select autism and not select learning disability, autism appears as a subcategory of autism. There therefore may be some errors in separately coding learning disability and LD.

5.2.9.3 LDA inpatients

According to data from the Mental Health Services Data Set (MHSDS 2017) in December 2017 there were 85,291 people in contact with learning disabilities and autism services. This dataset does not separate those with autism and LD from the wider LD service population. There were 3,130 people with learning disabilities and/or autistic spectrum disorders in hospital, of which 1,405 were in a secure setting. 1010 (32%) of those with LD and/or autism had been in hospital for over 2 years. 155 (5%) of those in hospital had a delayed discharge.

The table below displays the number of people accessing inpatient services for people with a learning disability and/or autistic spectrum disorder (LDA). This includes those with a bed normally designated for the treatment or care of people with LDA or a bed designated for mental illness treatment who have an LDA.

	September 2017	October 2017	November 2017	December 2017
Norfolk	35	35	40	35
England	3165	3160	3110	3125

Table 14 - People accessing inpatient services for a learning disability and/or autistic spectrum disorder (LDA)



5.3 Place

5.3.1 Adults (age 16-64) by district

Age group	2017	2020	2025	2030	2035
Breckland	767	774	778	776	782
Broadland	704	704	707	705	701
Great Yarmouth	562	561	559	560	561
King's Lynn and West Norfolk	837	839	839	831	829
North Norfolk	533	533	531	527	526
Norwich	949	962	988	1011	1026
South Norfolk	727	742	768	778	789
Norfolk	5080	5117	5165	5191	5211

Table 15 - Adults (age 16-64) with autism in Norfolk by district

Table 15 illustrates that the district with the greatest number of adults living with autism is Norwich, and the district with the lowest estimated number of adults living with autism is North Norfolk, followed by Great Yarmouth. However, these estimates do not take into account differences in socioeconomic status (SES) and urban/rural differences. As autism is associated with both lower SES and living in an urban area, numbers for Great Yarmouth, for example, may be underestimates.

5.3.2 Older adults by district



Table 16 illustrates the estimated number of older adults (65+) with autism by district.

Age group	2017	2020	2025	2030	2035
Breckland	322	338	376	422	466
Broadland	307	325	353	389	427
Great Yarmouth	225	237	253	279	302
King's Lynn and West Norfolk	366	384	421	464	503
North Norfolk	319	336	368	402	432
Norwich	189	197	210	234	260
South Norfolk	30	742	768	778	789
Norfolk	2039	2143	2340	2597	2826

Table 16 - Older adults (age 65+) with autism in Norfolk by district

5.3.3 By CCG

National prevalence data can also be applied to the most up to date population data for each CCG in Norfolk (ONS 2017), producing estimates of the numbers of adults and older adults with autism, and with autism and LD, by CCG (Table 17, Table 18).

Norfolk and Waveney CCG 2016 ONS resident population estimates	Population age 16-64	Autism (1% prevalence)	Autism with LD (55% of those with autism)
Great Yarmouth & Waveney	123,856	1239	681
North Norfolk	95,666	957	526
Norwich	141,383	1414	778
South	134,272	1343	739
West Norfolk	102,187	1022	562
Norfolk	597,364	5974	3286

Table 17 - Autism and autism with LD by CCG (age 16 to 64)

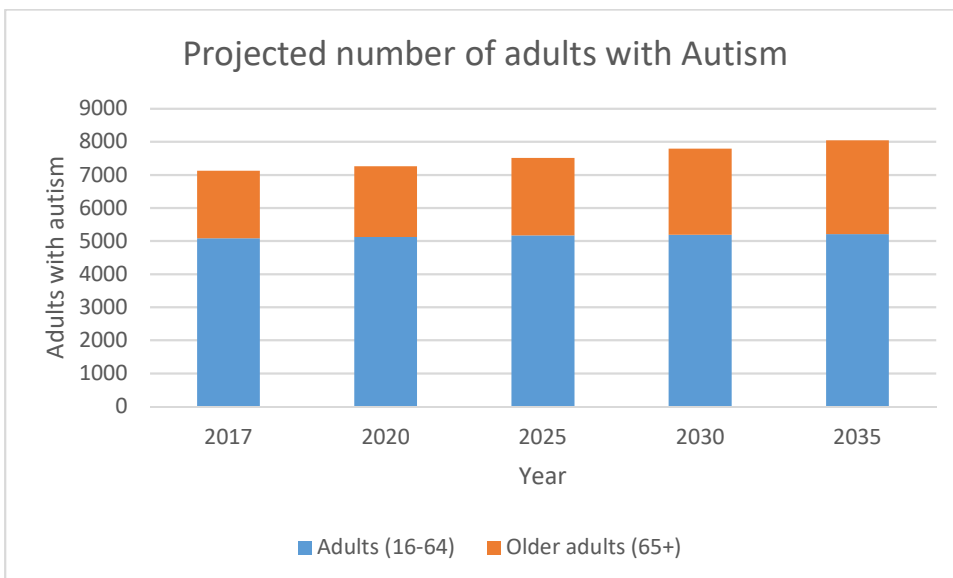
Norfolk and Waveney CCG 2016 ONS resident population estimates	Population age 65+	Autism (1% prevalence)	Autism with LD (55% of those with autism)
--	--------------------	------------------------	---



Great Yarmouth & Waveney	54,259	543	299
North Norfolk	50,223	502	276
Norwich	39,067	391	215
South	54,939	549	302
West Norfolk	45,408	454	250
Norfolk	244,006	2439	1341

Table 18 - Autism and autism with LD by CCG for older adults (age 65+)

5.4 Time



The number of adults with autism is projected to increase by a relatively small proportion as the population of Norfolk increases. However, the projected numbers of older people with autism are projected to increase significantly with the ageing population of the county. This has important implications for provision of health and social care for older people, as there will be more individuals who also have autism which may not have been diagnosed but may impact an older person receiving care at home or moving into a residential or care home.

5.5 Health inequalities



5.5,1 Inequalities between those with autism and the general population

People with autism are likely to experience health inequalities when compared with those without autism (Shropshire Council 2016). Contributing factors include lower attainment at school, reduce access to employment, social exclusion associated from their condition and access to housing. These social determinants of health influence lifestyle factors including diet and exercise. Improving access to education, health and social care services may help reduce these health inequalities.

5.5.2 Healthcare outcomes

A case-control study by Hirvikoski et al. suggested significantly higher mortality in almost all analysed diagnostic categories for people with autism compared to the general population in Sweden (0.91% of individuals in the general population died during the study period from 1987 to 2009, compared 2.60% of those with autism (OR=2.56, 95% CI 2.38 to 2.76) (Hirvikoski et al. 2016). The average age of death for people with autism was 53.87 years, compared with 70.2 for people without.

5.5.2.1 Mental health

In the study by Hirvikoski et al., (2016) people with autism were more likely to die than those without due to any of the causes considered, but in particular, deaths due to suicide were significantly increased. People with autism were 7.55 time more likely to die by suicide, with those without a learning disability, and women, at greater risk.

There is a need to better support people with autism to access universal services, including support for improving mental wellbeing. The 5 ways to wellbeing are evidence based actions that can be taken to promote mental wellbeing (Milton Keynes Council 2018), and which those with autism should be support to participate in if they wish to.



Figure 3 - 5 ways to wellbeing (Milton Keynes Council 2018)

5.5.3 Access to services for vulnerable groups

NICE guidance (2016) on the care of adults with autism emphasises the need for development of local autism care pathways that promote access to services for all, including those with coexisting physical and mental disorders (including substance misuse), women, people with LD, older people, ethnic minorities, transgender people, homeless people, travellers, parents with autism and people in the criminal justice system.

NICE guidance for children and young people with autism (2013) highlight the importance of supporting children with particular needs, including looked-after children, those from immigrant groups, those with regression in skills and those with coexisting conditions including physical or intellectual disability, communication impairment or mental health problems.

5.5.4 Socioeconomic status

Studies conducted in the USA have consistently suggested an association between higher socioeconomic status and autism (Rai et al. 2012), and some studies have found similar results in the UK. A study conducted in Bristol found an association between autism and fathers with a non-manual occupation (75.3% non-manual in autism cases vs. 55.8% in controls, $p=0.001$) (Williams et al. 2008) and another UK study identified an association between higher social class and pervasive



developmental disorder diagnosis, although this was not statistically significant (Fombonne et al. 2001).

However, it has been suggested this finding is due to bias in case ascertainment, with higher autism awareness and better access to diagnostic and support services among higher socioeconomic groups. A Swedish study suggested that in a country with free universal healthcare, routine screening for developmental problems and thorough autism diagnostic protocols that children with families with lower income and manual occupations were at higher risk of autism (odds ratio 1.4, 95% CI 1.3 to 1.6) (Rai et al. 2012). This relationship was present after controlling for parental age, migration status, parity, psychiatric service use, maternal smoking in pregnancy, parental education, birth characteristics and intellectual disability. A cross-sectional study conducted in England identified a significant association between autism and eligibility for free school meals (odds ratio 1.36, 95% CI 1.32 to 1.40) (Emerson et al. 2010).

5.5.5 Children in Need, Looked after children and child protection plans

5.5.5.1 Looked after children (LAC)

As of April 2018 there are 1179 recorded looked after children in Norfolk, 32 of whom are recorded as having a disability classification of “Diagnosed with Autism or Asperger Syndrome”.

5.5.5.2 Children protection plans (CPP)

As of April 2018 there are 560 children with a child protection plan, 6 of whom have a disability classification of “Diagnosed with Autism or Asperger Syndrome”.

Note there is some overlap between those who are looked after and those who have a child protection plan. There are 37 children who appear in both of these groups, none of whom are recorded as having a diagnosis of autism.



5.5.5.3 Children in Need (CIN)

As of April 2018 there are 1883 children recorded as CIN, excluding any LAC or CP children. Of these, 120 a disability classification of “Diagnosed with Autism or Asperger Syndrome”.

Data is not routinely collected on the number of parents with autism whose children are known to Children’s Services.

5.5.6 Gender

A survey by the National Autistic Society suggested diagnosis is particularly difficult and protracted for women and girls (Bancroft et al. 2012). One fifth of women and girls were diagnosed with Asperger syndrome or high-functioning autism by the age of 11, compared with half of men and boys. 42% were initially misdiagnosed with another condition compared with 30% of men and boys. This may be because autism is more common or perceived to be more common in men and boys and/or because it presents differently in women and girls. The survey also suggested differences in provision of effective support, with 49% of women and girls with Asperger syndrome or autism without LD saying diagnosis made no difference to the support they received, compared with 39% of men and boys.

5.6 Data gaps

5.6.1 Local gaps

- There is no universal, central collection of prevalence data for autism in Norfolk. Instead, estimates have been made based on the size of the local population and estimates of autism prevalence from the research literature. This is in part because some people do not have a diagnosis. Among those who do have a diagnosis, many do not access any services where data on autism diagnosis is collected. Among those who do access services, their autism diagnosis may not be recorded, and some data sets do not separate



those with autism from those with learning disabilities. Whilst 55% of people with autism have LD, 45% do not, and autism is not a learning disability.

- There is no Norfolk specific data on numbers of people on different parts of the autistic spectrum. Again, these have been estimated based on the size of the population and estimated proportions of people on different parts of the autistic spectrum from research studies.
- In July 2017 NICE proposed a new set of QOF indicators for potential inclusion in the NICE indicator menu for general practice, one of which was “Autism: The practice establishes and maintains a register of all patients with a diagnosis of Autism” (NICE 2017). This would likely significantly improve the collection of data on adults with autism, bringing this in line with the data on children collected through the Public Health Outcomes Framework (PHOF) indicator ‘Children with autism known to skills’, but both would still miss undiagnosed cases of autism or those not accessing GP or education services, such as the homeless or traveller communities, potentially exacerbating health inequalities.
- There are some specific issues with the way data is collected locally on autism among adult social care. There are some issues with the way in which the form this data is recorded on is designed and used, particularly in relation to those with autism without a learning disability. On the form, whilst it is possible to select autism and not select learning disability, autism appears as a subcategory of autism. There therefore may be some errors in separately coding learning disability and LD.

5.6.2 National gaps

- Knapp et al., in an economic evaluation of the impact of autism, highlighted a lack of robust prevalence figures on the numbers of people on different parts of the autistic spectrum and with different impacts on functioning. The only robust prevalence data they were able to identify were those relating to numbers of people with autism with or without a learning disability (e.g. Baird et al. 2006).



7. Experience of other areas (Comparative Needs Assessment)

7.1 Summary of experiences in other areas

- Community and voluntary organisations play an important role in providing support for people with autism.
- Many areas have identified gaps in provision of preventative services, to avoid the need for escalation to specialist services or to prevent escalation of behavioural issues.
- Many areas have highlighted a gap in services for people with autism who do not have a co-morbid learning disability or mental health problem and so are not eligible for these services.
- Those with autism and a mental health problem may not access services as often as the general population with mental health problems, leading to health inequalities.
- There is a need for improved access to universal services for people with autism by increasing awareness and training about autism among service providers so they can identify people with autism and make reasonable adjustments.

A rapid review of needs assessments for people with autism in other local areas was conducted to try to learn from their experiences.

7.2 Key gaps in service provision

As is highlighted in the national Autism Strategy, many local needs assessments for people with autism highlight how adults with autism without LD often fall through gaps in diagnostic and support services, fitting neither the remit of learning disability or mental health services (York City Council 2016).



A lack of autism awareness and training among staff providing universal services was also highlighted in several areas as a barrier to access and reasonable adjustments in universal services for people with autism (York City Council 2016; Haringey Borough Council 2017).

A need for preventative services to reduce escalation of mental health conditions and challenging behaviour among people with autism was also highlighted (Haringey Borough Council 2017).

7.3 Learning from other service models

Haringey Council identified some services as particularly effective, including special schools and autism teams supporting teachers in mainstream schools, the voluntary and community sector for supporting parents and advocacy, and specialist dentists.

Service recommendations from other areas:

- Support development of social activities for adults with autism e.g. peer support or support to access mainstream social or interest-based groups, to meet the need for low intensity, social and preventative support (Haringey Borough Council 2017).
- Undertake a training needs assessment for key service providers (e.g. GPs, MH staff, adult social care, and police) and provide targeted and accessible basic autism training based on the findings of the training needs assessment (Haringey Borough Council 2017).

8. Relevant services and third sector organisations (up to date as of April 2018)

8.1 Diagnostic services

- Children up to 12 years old in Norfolk can access diagnostic services provided by Norfolk Community Health and Care NHS Trust after referral from



universal services, including educational support at schools, linked workers with universal services, early help teams and children's centres.

- Children up to the 6th birthday with suspected autism will be seen on the Consultant led pathway, and those 6-12 years old via the non-consultant led neurodevelopmental pathway (managed by psychology and nursing staff with medical oversight as required).
- Asperger Service Norfolk, part of Norfolk Community Health & Care NHS Trust, provides diagnosis and support for adults with Asperger syndrome and High Functioning Autism living in Norfolk.

The full Pathway for Recognition, Referral, Assessment Management and Support of possible Autism in Children and Young People for North, South, Norwich & West Norfolk can be accessed here: <https://www.autism-alliance.org.uk/wp-content/uploads/2018/01/Norfolk-ASD-Pathway.pdf>

8.2 Specialist Education Services

A variety of educational support is available across Norfolk for children and young people with autism. The majority attend mainstream schools, and additional support is available through the Norfolk Specialist Resource Bases (SRB) Programme where necessary. There are a range of special schools available, both state funded and independent, many of which aim to cater for those with autism who have complex learning needs (details available [here](#)). There is one state funded special school in Norfolk specifically for pupils diagnosed with autism (The Wherry School).

8.3 Acute liaison services

- James Paget University Hospital, Queen Elizabeth Hospital King's Lynn and Norfolk and Norwich University Hospitals have acute liaison nursing services, who work with people autism and/or learning disabilities, their families and carers to provide information and support prior to, and during, admissions and outpatient appointments.



8.4 Community Dental Service for People with Learning Disabilities

Dental services for people with additional needs in Thetford are available.

<http://www.heron.nhs.uk/heron/organisationdetails.aspx?id=22326>

8.4 Voluntary and third sector services

Some relevant voluntary and third sector organisations are listed below. Further information can be found on Heron, a database of self-help support groups and statutory and voluntary agencies across Norfolk and Waveney

(<http://www.heron.nhs.uk/>).

8.5.1 Autism Anglia

- Autism Anglia provide support, advice and guidance to families and professionals.
- Autism Anglia also have a directory of child and adult support and activity groups, some of which are specifically for those with autism, some of which focus on people with disabilities and some of which are universal. This can be accessed here: <https://www.autism-anglia.org.uk/norfolk-support>

8.5.2 National Autistic Society (NAS)

- Provide information and advice for autistic people and their friends and families
- Run a range of services including residential services, supported living, community day hubs, outreach, befriending, social groups and employment support services for adults and specialist schools, autism centres in mainstream schools and further education support for children and young people.
- Support professionals by providing training courses and conferences.
- Participate in policy and advocacy work.



8.5.2.1 National Autistic Society (NAS) West Norfolk Branch

- Voluntary run by parents and carers with children or young people on the autistic spectrum. Organise coffee meetings providing opportunities for families to socialise, and often invite professionals to attend and deliver workshops and seminars.
- Have a library of autism related books.
- Arrange a wide variety of events including a fortnightly teenage group, monthly Saturday Club, music sessions, Lego club and holiday activities such as gym sessions, roller skating, soft play and swimming.
- <http://naswestnorfolkbranch.wbeden.co.uk>
- <https://www.facebook.com/naswestnorfolk/?fref=ts>

8.5.3 Asperger East Anglia

- Offers personal, friendly assistance for everyone with Asperger syndrome and their carers by providing a comprehensive and integrated service.
- Aim to work in partnership with other organisations to fill any gaps in service provision.
- Provide information on Asperger syndrome to professionals in the education, social care and health sectors.
- <http://www.asperger.org.uk/>

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