

## **Evidence Review: Health Needs of People with Autism**

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## 1. List of abbreviations

Abbreviation	Meaning
ASD	Autistic spectrum disorders
SEND	Special educational needs and disabilities
DHSC	The Department of Health and Social Care
NICE	National Institute for Health and Care Excellence
APPGA	All Party Parliamentary Group on Autism
ONS	Office for National Statistics
EHCP	Education, Health and Care Plan
NHS	National Health Service
SCC	Suffolk County Council
LGA	Local Government Association
PHE	Public Health England
ADASS	Association of Directors of Adult Social Services

## 2. Introduction

This evidence review was undertaken as part of a wider Health Needs Assessment for people of all ages with autism in Suffolk. The review was undertaken by public health professionals in Suffolk County Council, between August and December 2022. The aims of the evidence review were:

- i) To systematically identify and appraise evidence relating to the health and social needs of, and inequalities faced by, people with autism;
- ii) To identify national policies and guidance for 'best practice' relating to the care of people with autism.

## 3. Methods

A wide range of academic and non-academic literature, including guidelines, was sought, to fulfil the aims of the review. Academic literature was systematically identified through searching of EBSCO databases and grey literature sources including LGA, DHSC, PHE, DOH, NHS England.

The full search strategy was as follows:

((((Autistic spectrum disorder OR ASD OR Autism spectrum condition OR ASC OR Autism OR Asperger's) AND ("Health inequalit\*" OR "physical health" OR "emotional well being" OR disability\* OR "life expectanc\*" OR "mental illness" OR "suicide rate\*" OR "Access to services" OR diagnosis OR therapy) OR (quality OR "experience of care") OR "patient satisfaction" OR (Behavioural OR "lifestyle risk\*") OR (smoking OR alcohol\* OR "Wider determinant\*" OR "quality of housing" OR income OR homeless\* OR education OR unemployment OR environment) AND (Framework\* OR "best practice"

OR guideline\* OR polic\* OR standard\* OR provision\* OR recommendation\* OR intervention\* OR strateg\* OR “action plan” OR checklist\*)) [English] [2012-2022]

IN undertook initial literature search. AR screened abstracts for inclusion and identified further relevant sources through reference lists and widening of the above search, as new relevant topics emerged from findings. AR undertook data extraction and critical appraisal of sources.

## **4. Background**

### ***i. Definition of Autism***

Autism is a lifelong neurological and developmental disorder that affects how people interact with the world. The term ‘autism’ encompasses a wide range of conditions, including autism, Asperger's syndrome and atypical forms of autism.

People with autism often find it difficult to understand what others are feeling and express what they are feeling themselves. It is common for people with autism to have altered sensory perceptions and sometimes find particular sensations distressing. People with autism also frequently exhibit repetitive speech and movements, seem compelled to follow specific routines and be resistant to change. The severity and signs of a person's autism may alter over their lifetime and fluctuate depending on their environment and circumstances. Some people with autism have co-existing medical conditions or learning disabilities, but not all. (1)

In this document, the term ‘autism’ will be used to refer to all ‘autistic spectrum disorders’ (ASD). However, it is acknowledged that different individuals and groups prefer a variety of terms, including autistic spectrum condition, autistic spectrum difference and neurodiversity.

### ***ii. Causes of Autism***

Although the exact cause of autism is not known, it is thought that both genetic and environmental factors may play a role in the development of autism.

Autism occurs more frequently alongside some genetic conditions than in the general population, including in people with fragile X, tuberous sclerosis, Down syndrome and Rett syndrome (2). It is thought that overall, inherited genes or chromosomal disorders account for somewhere between 40 and 90% of autism cases (3). Research is ongoing into other potential risk factors for autism, including increased maternal age, prematurity at birth, and prenatal exposure to certain medications. Despite widespread concern following a now retracted paper published in the Lancet journal in 1998, there is no evidence that vaccines cause autism. (2)

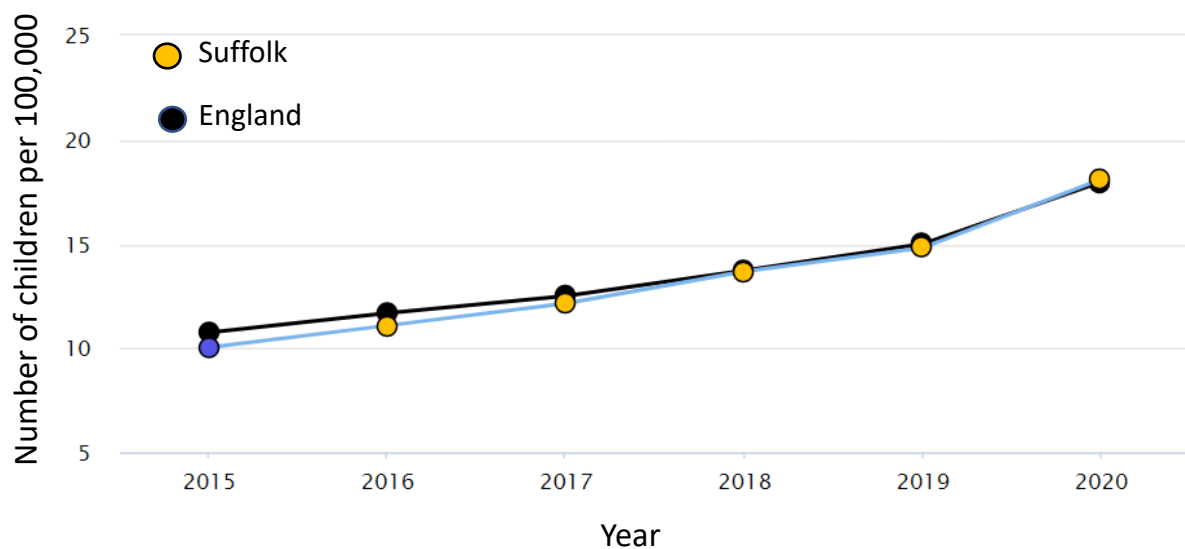
### ***iii. Epidemiology***

In the UK there are an estimated 700,000 adults and children with autism. This is roughly 1% of the population, which means that most individuals know someone who has autism. In addition, there are an estimated 3 million family members and carers of autistic people in the UK. (4)

In Suffolk, around 5,000 adults (aged 16 and over) are estimated to have autism<sup>1</sup>. In 2020, 1,870 pupils in Suffolk (in state-funded primary, secondary or special schools) had 'Autism Spectrum Disorder' as their primary Special Educational Needs (SEN) support reason. The number of children with autism known to schools has been increasing in Suffolk over recent years, similar to the national trend for England (see in Figure 1). This trend is unlikely to reflect an increase in prevalence of autism (5), rather system changes over time leading to increased diagnosis. These changes include a widening of diagnostic criteria, increased awareness of autism signs and symptoms amongst clinicians and the public, and increased service provision for people with autism (6).

Males are diagnosed with autism around 3 to 5 times more than females. Rather than autism being more common in males, this difference is thought to be a result of under-diagnosis of autism in females, due to autistic traits in women being less commonly reported, and women being more likely to "camouflage" their difficulties, altering their behaviours to fit in with societal expectation. (7)

**Figure 1: Children with autism known to schools in Suffolk compared to England**



## 5. Policy context

### *International*

After autism was brought to the attention of World Health Organisation (WHO) Member States in 2007, 2<sup>nd</sup> April was designated as World Autism Day, following which there has been a substantial increase in autism awareness internationally. In 2012, the United Nations General Assembly adopted a resolution addressing the socioeconomic needs of people with autism, advocating for access to

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<sup>1</sup> Adult Psychiatric Morbidity Survey 2007 & 2014 combined prevalence applied to Suffolk population projection for 2022.

appropriate support services and equal opportunities for people with autism, including through inclusive education systems and increased autism research. Also in 2012, the World Health Assembly also considered childhood mental disorders, including autism, and adopted a resolution urging member states to promote childhood mental health, and provide comprehensive support, from early identification to social care and treatment. (8)

According to the WHO, national responses to autism should prioritise:

- The development and implementation of policies, laws and services co-produced by people with autism and their families and stakeholders from all relevant sectors;
- The integration of health and social care services in community settings;
- The promoting health and preventing life-long disabilities for people with autism through multisectoral approaches, reduction of stigmatisation, discrimination and human rights violations;
- Improving information systems, surveillance and research capacity around autism and autism services. (8)

### ***National***

In the UK, autism is the only long-term condition with a condition-specific Act of Parliament: the 2009 Autism Act. This Act provides a structure for the improvement of the lives of people with autism and their families, and has been supported by Strategies and Statutory Guidance issued by the Department of Health and Social Care (DHSC), formerly Department of Health, including Think Autism in 2014 and Statutory Guidance for local authorities and NHS organisations in 2015. (9)

In 2021, the DHSC in combination with Department of Education and NHSE published 'The National Strategy for Autistic Children, Young People and Adults 2021-2026' (4) which updated the national strategy for the first time and clearly stated commitments to people with autism under 18 years of age. (9)

Other key legislation includes the Care Act 2014, the Children and Families Act 2015, as well as the 2019 NHS Long Term Plan which commits to reducing inequalities in provision to autistic people. The Mental Health Act and Special Educational Needs (SEND) reforms are due in 2022 (9).

### ***Suffolk***

In Suffolk, the Transforming Care programme works to improve the lives of children, young people and adults with autism and/or a learning disability. The key aims of the programme are:

1. To improve quality of care for people with a learning disability and/or autism
2. To improve quality of life for people with a learning disability and/or autism
3. To enhance community capacity, thereby reducing inappropriate hospital admissions and length of stay (10)

Specialist Social Work and Contracts and Service Development teams manage Transforming Care and out of county contracts, and facilitate the development of the revised Learning Disability Strategy and the All-Age Autism Strategy. (11)

A working group was established in 2021 to procure a contract to tender an All-Ages Autism strategy for Suffolk. This strategy will be formed through co-production with relevant stakeholders and people with autism and their families and will inform services and support offered in Suffolk. (11)

## **6. Health and Social Inequalities in Autism**

Health inequalities are avoidable differences in health of those with autism compared to those without autism (12). These differences may result from individual behaviours, accessibility and quality of health and care services, and wider determinants of health, otherwise known as social inequalities.

Social inequalities result from unequal distribution of resources in society, and are seen in areas including housing, employment and education. (13) These inequalities are not independent but interrelated, feeding into each other, and concentrating themselves in disadvantaged parts of the population. These inequalities may be further compounded by socioeconomic status and race (14).

For people with autism in England, the 2022 NHS five-year research strategy identified five major areas in which people with autism experience health inequalities, which will be examined in this report: 1) mental health; 2) physical health and disability; 3) mortality; 4) wider determinants of health; 5) barriers to accessing care. (15)

### **1. *More mental ill-health***

The prevalence of many mental health conditions is higher in individuals with autism than in the general population, highlighting the need for integrated mental health care and diagnosis with autism services. In a large 2019 review of over 100 studies of people with autism, an estimated 28% of people with autism were found to also suffer from attention-deficit hyperactivity disorder (compared to 7.2% in the general population), 20% with anxiety disorders (7.3% in the general population), 11% with depressive disorders (4.7% in the general population), and 4% with schizophrenia and psychotic spectrum disorders (0.46% in the general population) (16). Another evidence review found anorexia nervosa to have consistently higher prevalence in autistic compared to non-autistic individuals, although actual prevalence is still unknown (17).

#### *Risk factors for depression and suicide*

Multiple risk factors have been identified for depression and suicide for people with autism. A UK survey found that risk factors for suicidality in autistic adults included having a higher number of unmet support needs (identified by individuals as areas in which they would ideally like support but don't have it), previous self-harm without suicidal intention, and the act of "camouflaging", i.e., trying to hide autistic traits to cope in social situations. (18)

A 2018 study of people with autism in Australia found that lack of companionship and connection with others and lower levels of social support (the number of people an individual with autism felt they could "count on" for help or support) were risk factors for both depression and suicidal ideation in people with autism. (19)

Lastly, a large Swedish study identified people with autism without a learning disability to be at higher risk of suicide than those with a learning disability. (20)

### **2. *Poorer physical health and disability***

People with autism are more likely to have long-term health conditions than their non-autistic counterparts. Data drawn from the Scotland census showed that prevalence of physical disability was almost 16 times higher in autistic than non-autistic individuals (21). A large survey study of over 2000 individuals in 2019 found that in women, cardiovascular conditions were 1.4 times more likely in those with autism than those without, respiratory conditions, including asthma, were twice as likely, and diabetes 1.7 times as likely. The study found heart arrhythmias three times more likely to occur in both men and women with autism compared to without autism. (22) The prevalence of epilepsy, gastrointestinal disorders and autoimmune conditions has also been found to be higher in those with autism than the general population (23,24).

### *Learning disability in autism*

Around 40% of people with autism are thought to have a learning disability (25). A person with a learning disability has a significantly reduced ability to understand complicated information and learn new skills, and also reduced ability to be independent. Learning disabilities usually begin before adulthood but have a lasting effect. It is thought that the prevalence of learning disability is almost 50 times higher in autistic than in non-autistic individuals (21).

### **3. Earlier mortality**

Sadly, studies show that people with autism, on average, die younger than people without autism (15): a 2016 study found that mean age of death in people with autism was 54 years of age compared to 70 years of age for those without autism (20). This higher mortality occurs in both males and females with autism, and in those both with and without learning disability; however, excess mortality is significantly higher in those with a learning disability (20).

When analysed by specific cause of death, diseases relating to the nervous system and suicide were the two areas that had greatest difference between cause of death in autistic versus non-autistic people (both around seven times more likely) (20), with epilepsy the leading cause of death for autistic people with learning disability and suicide the leading cause of death for autistic people without a learning disability. Suicide was the only cause of death for which the risk was higher in those without a learning disability compared to those with one, which may be due to high prevalence of mental health conditions in autistic individuals without learning disabilities (20).

It is highly likely that other factors, including lack of adequate provision of, and difficulty accessing, appropriate health and social care, contribute significantly to these differences and are important aspects to target in order to address this inequality (26).

### **4. Worse wider determinants of health**

#### **i) Education**



The All Party Parliamentary Group on Autism's (APPGA) The Autism Act, 10 Years On report published in 2019 highlighted inadequate provision for children with autism in schools, with autistic children too often being held back and not accessing the opportunities they needed (27). The report stated that 40% of parents of autistic children said the school did not meet their child's needs. Special educational needs assessments took too long to be carried out, with 42% of parents of autistic children stating that their initial request for an assessment was refused, and 50% stating that it took over a year for school support to be provided. Teachers were found to be ill-prepared to support children with autism, with fewer than half of teachers stating they were confident in providing support. Six out of ten children with autism felt that having a teacher who understood autism was the main factor that would improve school for them (27).

As a result of APPGA report recommendations, the Government's national strategy for autistic people 2021-26 focuses on providing a more inclusive culture for autism in schools and improving SEND provision. Steps being taken include providing funding for staff autism training in schools and colleges, and making autism a priority within school leadership programmes to increase awareness and inclusivity. The government has also committed to opening 24 new special free schools across the country which will have provision for autistic children and young people. (4)

## **ii) Employment**

Office for National Statistics (ONS) figures highlight a low level of employment amongst people with autism, with only 29% of people in the UK with autism aged 16 to 64 in employment in the year ending June 2021 (28). Employment is lower for people with autism than for all people with disability (54%) and much lower than for non-disabled people (82%) (28).

The Autism Act, Ten Years On report found that multiple factors contribute to the low level of employment for people with autism, including difficulty accessing support that is needed to find employment or whilst working, and recruitment processes not being well set up for people with autism. The report found that many employers are in need of more advice regarding hiring people with autism, with 31% believing that people with autism would require too much support (27).

The 2021-26 government strategy includes employment support for people with autism, through measures such as: increasing employer awareness of autism and supporting employers through the Disability Confident Scheme; making Jobcentres more welcoming and supportive to people with autism; promoting the Access to Work scheme as a source of practical and financial support to people with disabilities including autism; continuing the Intensive Personalised Employment Support Programme to provide pre-employment support to help individuals overcome barriers to entering work. (4)

## **iii) Housing**

There is emerging evidence that amongst people who are homeless, prevalence of autism is higher than in the general population (29), a finding supported by high levels of unemployment in the autistic population. To improve housing for people with autism, the UK government have designated 10% of the new Affordable Homes Programme to be supported housing, available by 2026. The government is also working to support local authorities to access the Disabled Facilities Grant for

individuals with autism requiring home adaptations, with the aim of facilitating independent living. (4)

#### **iv) Socioeconomic status**

Socioeconomic factors are likely to contribute to the lives of people with autism in many ways, from diagnosis, to accessing support and further opportunities.

A large study in Bradford, UK, found that maternal level of education determined likelihood of autism diagnosis, as children of mothers educated to A-level or above were twice as likely to be diagnosed than children of mothers with educational attainment below A-level (6). Reasons for this may be that, given limited provision of diagnostic services with difficulties around access, receiving an autism diagnosis requires time, advocacy and perseverance on the part of the parent, along with initial awareness of the condition itself and ability to navigate a potentially complex system. (6) These findings, conversely, suggest an underdiagnosis of children whose mothers are less educated.

Furthermore, a large-scale study of pupils in England found that socioeconomically disadvantaged children had a higher likelihood of having autism than those who were not disadvantaged. This may either be due to children from disadvantaged families being at higher likelihood of developing autism and/or having a child with autism increasing the risk of a family experiencing poverty. This effect was amplified in particular racial/ethnic groups, most prominently amongst Black pupils, for whom much of the higher prevalence identified (2.11% compared to national prevalence of 1.76%) was explained by social disadvantage. (30)

Socioeconomic status may also impact the lives of people with autism more widely; a review of studies on the impact of socio-economic status in autism found that young people with autism from low-income households in the US were less likely to access paid employment than those from higher income households. They were also less likely to participate in social activities, including spending time with friends and leisure activities in the community. (14)

#### **v) Intersection with race/ethnicity**

Prevalence of autism, as well as the experiences of people with autism, are likely to vary based on race and ethnicity.

A study of over 7 million children in England found that prevalence of autism differed considerably according to ethnicity/race, with highest prevalence in Black pupils (2.11%) and the lowest in Roma/Irish Travelers (0.85%). Prevalence also differed by geographical location. The effect of race/ethnicity on autism diagnosis was associated largely with socioeconomic status. Other possible reasons for differences between groups were biases involved in detection, referral or diagnosis, or actual difference in prevalence between different groups. (30)

The intersection of race/ethnicity and autism may pose added challenges. A review of research in the US found that autistic people from ethnic minorities were less likely to undertake preparation for university, or major in 'STEM' (Science, technology, engineering, and mathematics) fields whilst at university, than their white peers. The review identified multiple studies that found that people with

autism from racial/ethnic minorities were less likely to secure employment than their white peers. The review also identified evidence that compared to young white people with autism, African American young people with autism were less likely to spend time with friends. (14)

### **5. Greater barriers to accessing care**

People with autism face greater barriers to accessing healthcare than the general population (15). Barriers can be divided into those arising at the level of the patient, healthcare provider or health system (26).

At the level of the patient, sensory sensitivity that autistic people commonly experience can cause difficulty in tolerating unfamiliar clinical settings, physical examinations and procedures. Communication difficulties in autism mean autistic individuals may find it more difficult to relay symptoms and healthcare-related concerns to the healthcare professional and engage with investigations and treatments. Behaviours sometimes exhibited by people with autism, for example, repetitive behaviours, aggression, and self-harming behaviours, increase the likelihood of restraint being employed in healthcare settings to enable investigations and treatments to be undertaken. These experiences reduce the likelihood of a person with autism engaging with healthcare in the future. (26)

At the level of the healthcare provider, inadequate knowledge of healthcare professionals regarding autism can prevent healthcare professionals from understanding the health, communication and setting needs of autistic people. This means they may not adapt their way of working to best engage with and treat people with autism and may not take the health concerns of autistic people seriously. (26)

At the organisational level, continuity of care and collaboration between different aspects of the health and care systems is important to effectively manage all aspects of care for people with autism. If services do not effectively communicate and cooperate, people with autism are prevented from accessing good care. Secondly, time and resource constraints may preclude high quality service provision. Furthermore, if any aspects of care provided require payment at the point of access, these will be less accessible for those from lower-income households, causing inequality. (26)

Two large survey studies have identified pervasive barriers to healthcare for people with autism in the UK. In the first study, healthcare quality was found to be poorer for autistic adults than non-autistic adults. Patient-level barriers, such as sensory difficulties, increased anxiety and withdrawal in healthcare settings, and barriers at the level of healthcare provider, such as poor communication, were identified. (31)

The second study, which specifically investigated access to General Practice, found that 80% of adults with autism had difficulty visiting a GP, compared to 37% of adults without autism. The most common barriers by people with autism in accessing GP care were: at patient level, difficulty deciding if their symptoms warranted a GP visit; at the level of the healthcare provider, struggling to make appointments by telephone, not feeling understood, and difficulty communicating with their doctor; and at the organisational level, struggling with the waiting room environment. (32)

A majority of adults with autism stated that their care would be improved by: being able to email their GP in advance of their appointment with a description of their issue; being able to book an appointment by online or by text; and being able to wait in a quiet place or outside the surgery until

their turn. The study also reported that, despite people with autism being more likely than people without autism to feel their relationship with their GP was important to them, only 33% of people with autism reported having a good relationship with their GP. People with autism said they appreciated GPs that ask direct questions, give clear explanations and are honest about not understanding autism but know it is not a mental illness. (32)

## **7. Bullying and transition between child and adult services**

Children and young people with autism also face increased exposure to bullying than those without autism, and challenges associated with the transition from child to adult services.

### ***i) Bullying***

People with autism report high levels of bullying as children, with estimates of bullying in school for children with autism between 40 and 63% (33). A London-based study of 13 to 18 year olds with autism found that those who had been bullied had almost twice the risk of suicidal thoughts or behaviours compared to those who had not. (34) Victimisation and disability hate crime continues into adulthood, and the effects of bullying for people with autism can lead to development of challenging behaviour, increasing the likelihood of placement in institutional and restrictive settings. (33)

### ***ii) Transition from child to adult services***

The transition to adulthood and move to adult from child services often comes at a time of significant need for young people with autism (35). A review of studies examining access to healthcare found that a fast transition, with lack of coordination between services, or attention to individual needs, can be distressing (35).

The SEND Code of Practice states that for young people with autism, preparation for adulthood should begin early, specifically, for those with an EHC plan, from year 9 onwards. However, The Autism Act, Ten Years On report found that this does not always happen, with less than 30% of individuals surveyed having had adequate preparation time (27).

Furthermore, planning for adulthood should be a collaborative effort between education, health and social care services, but is often not the case, with the health and social care aspects often being inadequately addressed (27). Families described a lack of community services, and being unable to spend the direct payments they received on social support. Services were also poorly signposted, with families unsure which services within the local offer are available and appropriate for their children's individual needs. A UK study exploring the experiences of 16-25 year old people with autism found that they often had difficulty understanding their own mental health needs and faced high levels of stigma when trying to access mental health support. (36) Lack of opportunities to integrate socially leaves people with autism vulnerable to isolation and bullying, exacerbating mental health problems (27).

It is also possible that income and race/ethnicity decrease the likelihood of young people with autism accessing services during transition period, an inequality exposed in the US population (14).

## **8. Impact of COVID-19**

There is some evidence that the COVID-19 pandemic had a greater negative impact on people with autism than the general population. The National Autistic Society (NAS) 'Left Stranded' report found that people with autism in the UK had been seven times more likely to be lonely during June and July 2020 than people without autism (37). Government-commissioned research also found that for some people with autism, the pandemic led to increased anxiety for people with autism, due to heightened concern about the disease itself, the introduction of new infection control and lockdown measures, as well as challenges associated with social re-integration (37).

However, for some people with autism, the pandemic lockdown had positive effects, for example, affording greater freedom from societal expectations, decreasing encounters with discriminatory behaviour due to fewer social interactions, and enabling time to be spent more satisfactorily, for example ability to spend more time on special interests (37).

A study investigating healthcare quality for people with autism found no evidence of impact of the pandemic on quality of healthcare for people with autism, although people with autism generally experienced poorer quality of healthcare both before and after the pandemic than people without autism (31). This adds to evidence that people with autism often face greater barriers to good healthcare than the general population.

## 9. National frameworks and policies recommended for people with autism

National guidance is presented here in the following sections: i) for local partners; ii) for schools; iii) for families and communities; for professionals and frontline staff.

### *i. Guidelines for local partners*

<b>NICE (1)</b>
<b>General Principles of Care</b>
In order to effectively provide care and support for autistic adults, the local autism multi-agency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from autistic people and their families, partners and carers. (1)
In each area a specialist community-based multidisciplinary team for autistic adults (the specialist autism team) should be established. The membership should include: <ul style="list-style-type: none"><li>• psychologists with training and experience in working with autistic adults</li><li>• nurses</li><li>• occupational therapists</li><li>• psychiatrists</li><li>• social workers</li><li>• speech and language therapists</li><li>• support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills). (1)</li></ul>
The specialist autism team should have a key role in the delivery and coordination of: <ul style="list-style-type: none"><li>• specialist diagnostic and assessment services</li><li>• specialist care and interventions</li></ul>

- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for autistic adults (as not all may be in the care of a specialist team)
- support in accessing, and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for autistic adults living in specialist residential accommodation
- training, support and consultation for staff who care for autistic adults in residential and community settings. (1)

### **Developing Local Care Pathways**

Local care pathways should be developed to promote implementation of key principles of good care. Pathways should be:

- negotiable, workable and understandable for autistic adults, their families, partners and carers, and professionals
- accessible and acceptable to all people in need of the services served by the pathway
- responsive to the needs of autistic adults and their families, partners and carers
- integrated so that there are no barriers to movement between different levels of the pathway
- outcome focused (including measures of quality, service user experience and harm). (1)

Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway
- ensuring the provision of multi-agency training about features of autism, and training and support on the operation of the pathway
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- supporting the integrated delivery of services across all care settings
- supporting the smooth transition to adult services for young people going through the pathway
- auditing and reviewing the performance of the pathway. (1)

The autism strategy group should develop local care pathways that promote access to services for all autistic adults, including:

- people with coexisting physical and mental disorders (including substance misuse)
- women
- people with learning disabilities
- older people
- people from black and minority ethnic groups
- transgender people
- homeless people
- people from the traveller community
- people in the criminal justice system

<ul style="list-style-type: none"> <li>• autistic parents. (1)</li> </ul>
<p>The autism strategy group should design local care pathways that promote a range of evidence-based interventions at each step in the pathway and support autistic adults in their choice of interventions. (1)</p>
<p>The autism strategy group should design local care pathways that respond promptly and effectively to the changing needs of all populations served by the pathways. Pathways should have in place:</p> <ul style="list-style-type: none"> <li>• clear and agreed goals for the services offered to autistic adults</li> <li>• robust and effective means for measuring and evaluating the outcomes associated with the agreed goals</li> <li>• clear and agreed mechanisms for responding promptly to identified changes to people's needs. (1)</li> </ul>
<p>The autism strategy group should design local care pathways that provide an integrated programme of care across all care settings. Pathways should:</p> <ul style="list-style-type: none"> <li>• minimise the need for transition between different services or providers</li> <li>• allow services to be built around the pathway and not the pathway around the services</li> <li>• establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs)</li> <li>• have designated staff who are responsible for the coordination of people's engagement with the pathway.</li> <li>• Improving access to care (1)</li> </ul>
<p>There should be a single point of referral (including self-referral) to specialist services for autistic adults. (1)</p>
<p>Support access to services and increase the uptake of interventions by:</p> <ul style="list-style-type: none"> <li>• delivering assessment and interventions in a physical environment that is appropriate for people with hyper- and/or hypo-sensory sensitivities (see recommendation 1.1.8)</li> <li>• changing the professional responsible for the person's care if a supportive and caring relationship cannot be established. (1)</li> </ul>
<p>Support access to services and increase the uptake of interventions by:</p> <ul style="list-style-type: none"> <li>• ensuring systems (for example, care coordination or case management) are in place to provide for the overall coordination and continuity of care for autistic adults</li> <li>• designating a professional to oversee the whole period of care (usually a member of the primary healthcare team for those not in the care of a specialist autism team or mental health or learning disability service). (1)</li> </ul>
<p><b>Residential Care</b></p>
<p>If residential care is needed for autistic adults it should usually be provided in small, local community-based units (of no more than six people and with well-supported single person accommodation). The environment should be structured to support and maintain a collaborative approach between the autistic person and their family, partner or carer(s) for the development and maintenance of interpersonal and community living skills. (1)</p>
<p>Residential care environments should include activities that are:</p> <ul style="list-style-type: none"> <li>• structured and purposeful</li> <li>• designed to promote integration with the local community and use of local amenities</li> <li>• clearly timetabled with daily, weekly and sequential programmes that promote choice and autonomy. (1)</li> </ul>



Residential care environments should have:

- designated areas for different activities that provide visual cues about expected behaviour
- adaptations to the physical environment for people with hyper- and/or hypo-sensory sensitivities (see recommendation 1.1.8)
- inside and outside spaces where the autistic person can be alone (for example, if they are over-stimulated). (1)

Recommended max 13 weeks between referral and assessment

**“Building the right home”, issued by NHS England, the LGA and ADASS (38)**

In line with the service model, housing options should be based on individual need and be an integral component of the person-centred care and support plan.

Everyone should either be offered their own tenancy in settled accommodation or own their own home. This can be in small-scale supported living schemes or other bespoke housing options (examples are set out in the guidance).

Transforming Care Partnerships should consider producing a housing strategy, with a clear understanding of the types and volume of accommodation required, to facilitate the engagement of a variety of housing providers both within the local area and those with national provision.

**National government strategy (4)**

Disability equality training for transport operators, to provide knowledge on autism-friendly adjustments. Also, “It’s everyone’s journey” is aimed at helping the public to be more mindful of passengers, including those who are autistic, and the challenges they may face when using transport.

Contact with criminal justice system – put a couple of examples – should these be included? p.35 (4)

Sport England’s new strategy, launched in January 2021, is working to enable more people, including autistic people, to be physically active ... As part of this effort, Sport England will be working with key partners to engage more autistic people at all levels and in all forms of sport and physical activity, including across volunteering and coaching.

To improve employer confidence, we [DHSC] will continue to engage with employers through the Disability Confident Scheme. This provides advice and support to employers, and to promote the skills, talents and abilities of autistic people, as well as other disabled people.

[The government] will lead the way in becoming a more autism-inclusive employer by expanding our Autism Exchange Internship Programme, which is aimed at providing more autistic people with experience of working in the Civil Service.

We will continue to promote the Access to Work scheme, which provides a range of practical and financial support to disabled people, including autistic people. During the COVID-19 pandemic, this has been extended to ensuring those who are working from home can access equipment and support they need and will continue in the first year of this strategy.

To enable those who need more intensive support to get into work, we will continue to ensure that the Intensive Personalised Employment Support Programme (IPES) is open to autistic people who qualify.

There may be job centres in Suffolk that are more accessible than others (see DHSC (4)) ... “In addition, we will continue to promote the Autism Centre for Research on Employment’s (ACRE) free Autism Employment Profiling Service, which went live in October 2020 and enables Jobcentres to signpost and provide appropriate support to autistic people without a learning disability”

**NICE (39)**

### **Access to health and social care services**

Ensure that all autistic children and young people have full access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis.

### **Organisation and delivery of services**

The overall configuration and development of local services (including health, mental health, learning disability, education and social care services) for autistic children and young people, should be coordinated by a local autism multi-agency strategy group (for autistic people of all ages) in line with the NICE guidelines on autism in children and young people (covering identification and diagnosis) and autism in adults.

The assessment, management and coordination of care for autistic children and young people should be provided through local specialist community-based multidisciplinary teams ('local autism teams') which should include professionals from health, mental health, learning disability, education and social care services in line with the NICE guidelines on autism in children and young people (covering identification and diagnosis) and autism in adults.

Local autism teams should ensure that every child or young person diagnosed with autism has a case manager or key worker to manage and coordinate treatment, care, support and transition to adult care in line with the NICE guideline on autism in children and young people (covering identification and diagnosis).

Local autism teams should provide (or organise) the interventions and care recommended in this guideline for autistic children and young people who have particular needs, including:

- looked-after children and young people
- those from immigrant groups
- those with regression in skills
- those with coexisting conditions such as:
  - severe visual and hearing impairments
  - other medical problems including epilepsy or sleep and elimination problems
  - motor disorders including cerebral palsy
  - intellectual disability
  - severe communication impairment, including lack of spoken language, or complex language disorders
  - mental health problems.

Local autism teams should have a key role in the delivery and coordination of:

- specialist care and interventions for autistic children and young people, including those living in specialist residential accommodation
- advice, training and support for other health and social care professionals and staff (including in residential and community settings) who may be involved in the care of autistic children and young people
- advice and interventions to promote functional adaptive skills including communication and daily living skills
- assessing and managing behaviour that challenges
- assessing and managing coexisting conditions

- reassessing needs throughout childhood and adolescence, taking particular account of transition to adult services
- supporting access to leisure and enjoyable activities
- supporting access to and maintaining contact with educational, housing and employment services
- providing support for families (including siblings) and carers, including offering short breaks and other respite care
- producing local protocols for:
  - information sharing, communication and collaborative working among healthcare, education and social care services, including arrangements for transition to adult services
  - shared care arrangements with primary care providers and ensuring that clear lines of communication between primary and secondary care are maintained.

Refer autistic children and young people to a regional or national autism service if there is a lack of:

- local skills and competencies needed to provide interventions and care for a child or young person with a complex coexisting condition, such as a severe sensory or motor impairment or mental health problem, or
- response to the therapeutic interventions provided by the local autism team.

#### **Making adjustments to the social and physical environment and processes of care**

Take into account the physical environment in which autistic children and young people are supported and cared for. Minimise any negative impact by:

- providing visual supports, for example, words, pictures or symbols that are meaningful for the child or young person
- making reasonable adjustments or adaptations to the amount of personal space given
- considering individual sensory sensitivities to lighting, noise levels and the colour of walls and furnishings.

Make adjustments or adaptations to the processes of health or social care, for example, arranging appointments at the beginning or end of the day to minimise waiting time, or providing single rooms for children and young people who may need a general anaesthetic in hospital (for example, for dental treatment)

#### **Information and involvement in decision-making**

Provide autistic children and young people, and their families and carers, with information about autism and its management and the support available on an ongoing basis, suitable for the child or young person's needs and developmental level. This may include:

- contact details for local and national organisations that can provide:
- support and an opportunity to meet other people, including families or carers, with experience of autism
- information on courses about autism
- advice on welfare benefits, rights and entitlements
- information about educational and social support and leisure activities

- information about services and treatments available
- information to help prepare for the future, for example, transition to adult services.

Make arrangements to support autistic children and young people and their family and carers during times of increased need, including major life changes such as puberty, starting or changing schools, or the birth of a sibling.

Explore with autistic children and young people, and their families and carers, whether they want to be involved in shared decision-making and continue to explore these issues at regular intervals. If children and young people express interest, offer a collaborative approach to treatment and care that takes their preferences into account.

### **Families and Carers**

Offer all families (including siblings) and carers verbal and written information about their right to:

- short breaks and other respite care
- a formal carer's assessment of their own physical and mental health needs, and how to access these.

Offer families (including siblings) and carers an assessment of their own needs, including whether they have:

- personal, social and emotional support
- practical support in their caring role, including short breaks and emergency plans
- a plan for future care for the child or young person, including transition to adult services.

When the needs of families and carers have been identified, discuss help available locally and, taking into account their preferences, offer information, advice, training and support, especially if they:

- need help with the personal, social or emotional care of the child or young person, including age-related needs such as self-care, relationships or sexuality
- are involved in the delivery of an intervention for the child or young person in collaboration with health and social care professionals.

### **NICE (39)**

Local autism teams should ensure that autistic young people who are receiving treatment and care from child and adolescent mental health services (CAMHS) or child health services are reassessed at around 14 years to establish the need for continuing treatment into adulthood.

If continuing treatment is necessary, make arrangements for a smooth transition to adult services and give information to the young person about the treatment and services they may need.

The timing of transition may vary locally and individually but should usually be completed by the time the young person is 18 years. Variations should be agreed by both child and adult services.

As part of the preparation for the transition to adult services, health and social care professionals should carry out a comprehensive assessment of the autistic young person.

The assessment should make best use of existing documentation about personal, educational, occupational, social and communication functioning, and should include assessment of any coexisting conditions, especially depression, anxiety, ADHD, obsessive-compulsive disorder (OCD) and global delay or intellectual disability in line with the NICE guideline on autism in adults.
For young people aged 16 or older whose needs are complex or severe, use the care programme approach (CPA) in England, or care and treatment plans in Wales, as an aid to transfer between services.
Involve the young person in the planning and, where appropriate, their parents or carers.
Provide information about adult services to the young person, and their parents or carers, including their right to a social care assessment at age 18.
During transition to adult services, consider a formal meeting involving health and social care and other relevant professionals from child and adult services.
<b>National government strategy (4)</b>
Development of develop Supported Employment Forums in all local areas. Bring together employers, Jobcentres, education providers, Local Authorities, young people and their parents to discuss employment opportunities for young people with SEND in their local areas

**ii. Guidelines for schools**

<b>NICE (39)</b>
<b>Specific interventions for the core features of autism: Psychosocial interventions</b>
Consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. To be delivered by a trained professional.
<b>National government strategy (4)</b>
Introduction of an antibullying programme in schools
Introduction of Mental Health Support Teams in schools
Introduction of training for designated Senior Mental Health Leads within schools
A new qualification has been designed for early years staff who want to specialise in SEND
37 new special free schools across the country (from September 2022) of which 24 have provision specifically for autistic children and young people.

### iii. Guidelines for families and communities

<b>NHS(40)</b>
<b>Advice for families</b>
Seek emotional and practical support from friends and family
Get advice from other parents of autistic children or autistic adults. A directory support services is provided here: <a href="https://www.nhs.uk/conditions/autism/support/">https://www.nhs.uk/conditions/autism/support/</a>
Listen to other parents' stories, for example those provided by the charity <i>healthtalk.org</i>
Ask their local council for a carer's assessment, to find out their eligibility for extra support and financial benefits
Consider undertaking a course for parents of autistic children, such as the EarlyBird course from the National Autistic Society
Access The National Autistic Society guide for parents and carers for advice on how to tell a child about their diagnosis
Support siblings of children with autism by <ul style="list-style-type: none"><li>• Spending time with just them</li><li>• Talking to them about what is going on and asking if they have questions or worries</li><li>• Letting them have time on their own or with their friends, for example, sleepovers at friends' houses</li><li>• Accessing advice from Sibs, a charity for siblings of disabled children</li></ul>
<b>DHSC (38)</b>
<b>Local authorities</b>
Ensure that people have a variety of service providers to choose from, and that people have enough information to access the services that best meet their needs.
Access the 'What Good Looks Like' report to improve local service provision

### iv. Guidelines for professionals and frontline staff

<b>NICE (1)</b>
<b>Principles for working with autistic adults and their families, partners and carers</b>

All staff working with autistic adults should work in partnership with autistic adults and, where appropriate, with their families, partners or carers, and having an understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of the social and physical environment.

Health and social care professionals should:

- understand the impact on and interaction with other coexisting mental and physical disorders and their management
- understand the potential discrepancy between intellectual functioning and adaptive functioning, e.g., in planning and performing activities of daily living
- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- consider whether the person may benefit from access to a trained advocate.

Health and social care professionals should:

- explaining their role and function, and making sure they are easily identifiable
- addressing the person using the name and title they prefer
- checking that the autistic person understands what is being said and providing information in an appropriate language or format
- considering communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters (someone who does not have a personal relationship with the autistic person) if required.

Health and social care professionals should:

- familiar with recognised local and national sources (organisations and websites) of information and/or support for autistic people
- able to discuss and advise on how to access and engage with these resources.

Encourage autistic adults to participate in self-help or support groups or access one-to-one support, and provide support so that they can attend meetings and engage in the activities.

In all settings, take into account the physical environment in which autistic adults are assessed, supported and cared for, including any factors that may trigger behaviour that challenges.

If necessary make adjustments or adaptations to the: amount of personal space given, setting using visual supports, colour of walls and furnishings, lighting, noise levels. Consider varying the duration or nature of assessments/interventions to limit the negative impact of the environment.

Ensure that autistic adults who have caring responsibilities receive support to access the full range of mental and physical health and social care services, including information and training and social support to enable them to receive care and access education and employment.

**Involving families, partners and carers**

Discuss with autistic adults if and how they want their families, partners or carers to be involved in their care, taking into account any implications of the Mental Capacity Act (2005) and the person's communication needs.

If the autistic person wants their family, partner or carer(s) to be involved, encourage this involvement and:

- negotiate about confidentiality and sharing of information on an ongoing basis
- explain how these individuals can help support the autistic person and help with care plans
- make sure that no services are withdrawn because of involvement of the family, partner or carer(s), unless this has been clearly agreed with both the autistic person and their family, partner or carer(s).

Give all families, partners and carer(s) (whether or not the person wants them to be involved in their care) verbal and written information about:

- autism and its management
- local support groups and services specifically for families, partners and carers
- their right to a carer's assessment of their own physical and mental health needs, and how to access this (see the NICE guideline on supporting adult carers).

If an autistic person does not want their family, partners or carer(s) to be involved in their care:

- give the family, partner or carer(s) verbal and written information about who they can contact if they are concerned about the person's care
- bear in mind that this may be for many different reasons, including a coexisting mental disorder or prior experience of violence or abuse.

**Identification and assessment**

Offer all adults who have received a diagnosis of autism (irrespective of whether they need or have refused further care and support) a follow-up appointment to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require.

**Psychosocial interventions focused on life skills**

For autistic adults of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles.

For autistic adults without a learning disability or with a mild to moderate learning disability, who are socially isolated or have restricted social contact, consider a group-based or individual leisure activity programme.

Consider anti-victimisation interventions for autistic adults without a learning disability or with a mild learning disability, who are at risk of victimisation.

For autistic adults without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.

**Assessment and interventions for families, partners and carers**



Offer families, partners and carers of autistic adults an assessment of their own needs. When the needs of families, partners and carers have been identified, facilitate contact with a range of support groups including those specifically designed to address these needs. Also offer training and support for those who need help with care of the autistic person, including delivery of an intervention.

#### **Developing local care pathways**

Residential care staff should:

- understand the principles and attitudes underpinning the effective delivery of residential care for autistic adults
- work in collaboration with health and community care staff from a range of specialist services to support the delivery of a comprehensive care plan
- be trained in assessing and supporting the needs of autistic adults
- be consistent and predictable, but with some flexibility to allow change and choice
- be committed to involving families, partners and carers.

#### **National government strategy (4)**

Oliver McGowan Mandatory Training in learning disability and autism should be undertaken by health and adult social care staff. This will provide an understanding of adjustments required for people with autism, helping to tackle health and care inequalities.

Commissioners should undertake training provided by the Local Government Association (LGA), Skills for Care and the Association of Directors of Adult Social Services (ADASS). Commissioners should also access guidance to help them identify local demand and develop the right services for autistic people (published alongside government strategy)

#### **NICE (39)**

##### **Knowledge and competence of health and social care professionals**

Health and social care professionals working with autistic children and young people in any setting should receive training in autism awareness and skills in managing autism, which should include:

- the nature and course of autism and behaviour that challenges in autistic children and young people
- recognition of common coexisting conditions
- the importance of key transition points, such as changing schools or health or social care services
- the child or young person's experience of autism and its impact on them
- the impact of autism on the family or carers
- the impact of the social and physical environment on the child or young person
- how to assess risk and develop a risk management plan
- the changing needs that arise with puberty
- how to provide individualised care and support and ensure a consistent approach is used across all settings
- skills for communicating with an autistic child or young person

<b>Interventions for life skills</b>
Offer autistic children and young people support in developing coping strategies and accessing community services, including developing skills to access public transport, employment and leisure facilities.
<b>National government strategy (4)</b>
The National Assessment and Accreditation System (NAAS) simulated practice and knowledge assessment materials can be accessed by social workers working with autistic children.

## 10. Appraisal of Evidence

Author/organisation	Reference	Document type	Strengths	Major weaknesses, including applicability
NICE	(1,3,7,39)	Guidelines; Clinical Knowledge Summaries (CKS)	UK guidance by recognised national body; collation of up-to-date literature on autism	
Hodges et al.	(2)	Review of evidence	Recent review of prevalence, epidemiology and aetiology through review of high quality studies	Search strategy not provided
UK Government	(4)	Strategy document	Primary source for government autism strategy	Not peer-reviewed
Kelly et al.	(6)	Observational study (cohort)	Large sample size; UK setting	Associations in Bradford-born cohort may not be applicable to wider UK
Brugha et al.	(5)	Observational study (survey)	Adults of all abilities sampled, standardised diagnostic assessments used for comparability	Small number of individuals with autism included for analysis
WHO	(8)	Executive board report	Contains World Health Organisation's position on autism	

Local Government Association	(9)	Fact sheet	Collation of national laws, regulations and strategies	
Suffolk County Council	(10,11)	Information pages	Provides information on Suffolk's Transforming Care programme, Learning Disability Strategy and All-Age Autism Strategy	
NHS England, King's Fund	(12,13)	Fact sheets	Government information pages explaining healthcare inequalities and wider determinants of health	
Eilenberg et al.	(14)	Systematic review	Multiple studies examining impact of race and socioeconomic status for people with autism	Majority of studies set in USA
NHS England	(15)	Strategy document	Provides five-year autism research strategy for England	Quality of evidence in introduction not critically appraised
Lai et al.	(16)	Systematic review	Large sample size for investigation of prevalence of schizophrenia and psychotic disorders (n > 150,000)	High heterogeneity of studies
Westwood et al.	(17)	Literature review	Majority UK-based studies	Qualitative synthesis of data, small sample sizes, wide range of estimates for autism in anorexia nervosa patients
Cassidy et al.	(18)	Survey study	Statistical significance found for difference in camouflaging between females and males	Study only included individuals without learning disability
Hedley et al.	(19)	Survey study	Social support and loneliness statistically significant predictors of depression and suicidal ideation	Australian population; severe autism with learning disability not well-represented
Hirvikoski et al.	(20)	Matched case cohort study	Large sample sizes, high power	Swedish population
Rydzevska et al.	(21)	Cross-sectional study	UK-based (Scotland); census data so large sample size and likely representative	Self-reported data; only children and young people (up to 24 years) included
Weir et al.	(22)	Survey study	Large sample size	Self-reported data, severe autism and learning disability not well-represented

Lukmanji et al.	(23)	Systematic review	Large sample size	High heterogeneity of studies
Croen et al.	(24)	Cross-sectional study	Large sample size, included individuals across full range of intellectual ability, data from healthcare providers	US-based population
Autistica	(25)	Fact sheet		Literature not provided
APPGA	(27)	Report, survey	UK-based	Not peer-reviewed
ONS	(28)	Report	UK-based, large sample sizes, statistically significant findings	
Churchard et al.	(29)	Cross-sectional interview study	UK-based	Diagnosis of autism made by key workers, not clinicians
Roman-Urrestarazu et al.	(30)	Cohort study	UK-based, large sample size, data from school census so likely representative	
Walsh et al.	(26)	Systematic review	Large range of clinical settings included, study quality variable	Majority of studies US-based
Weir et al.	(31)	Cross-sectional survey study	Large sample size, majority UK residents	Self-reported data; individuals with learning disability not well-represented
Doherty et al.	(32)	Cross-sectional survey study	Large sample size	Self-reported data; individuals with learning disability may not be well-represented
Calleja et al.	(35)	Systematic review	Three studies investigated transition from child to adult services	Study settings varied; qualitative and quantitative outcomes meant effects not pooled
Crane et al.	(36)	Cross-sectional study	UK-based	Severe autism and learning disability not well-represented
Bradshaw et al.	(33)	Scoping review	Wide range of qualitative and quantitative literature	Not peer-reviewed
Holden et al.	(34)	Retrospective cohort study	UK-based, large sample size, clinical data used	
Pais et al.	(37)	Rapid literature review	UK-based	Not peer-reviewed, variable quality of evidence
NHS England, the LGA and ADASS	(38)	Guidance document	Guidance published on behalf of government organisations	

NHS	(40)	Information page	NHS information for families	
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