Chapter Seven: ADHD and Autism

Summary

Scope

This chapter looks at the mental health needs of autistic people and people with ADHD in Cambridgeshire and Peterborough, across all age groups. It aims to answer the following questions:

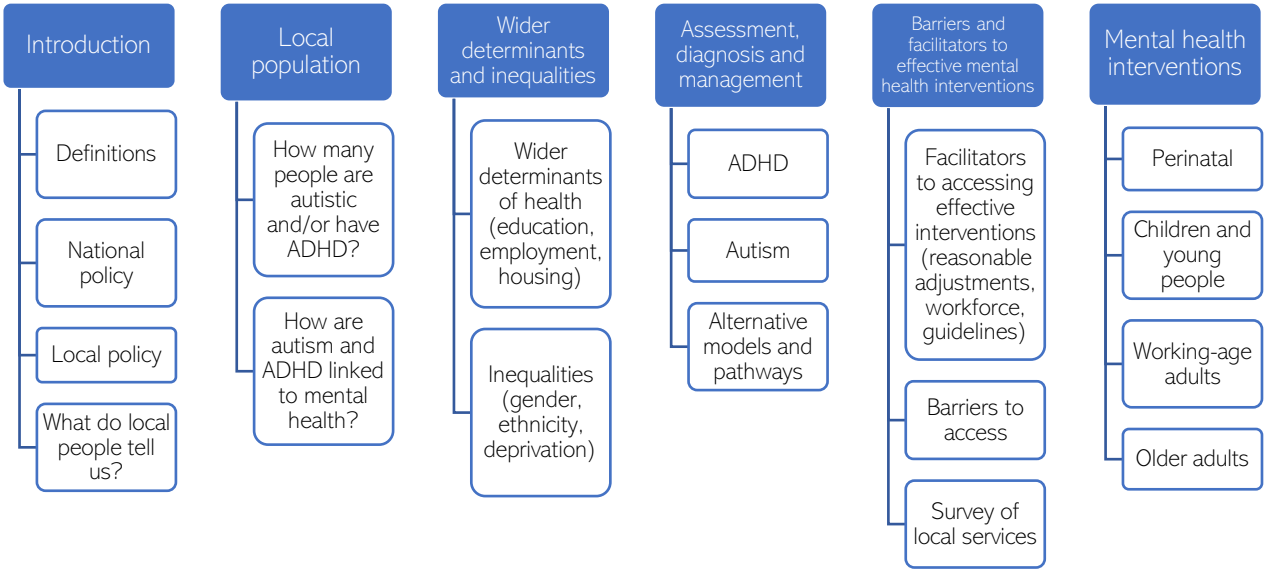
- How many people in Cambridgeshire and Peterborough are autistic and/or have ADHD?
- What is the current picture of ADHD and autism assessment services in Cambridgeshire and Peterborough?
- What are the risk factors for poor mental health faced by autistic people and people with ADHD?
- How many autistic people and people with ADHD have mental health needs?
- How are mental health services currently used by autistic people and people with ADHD, and how does this compare with expected need? What are the barriers and facilitators to accessing mental health services for these groups?
- What are the inequalities across the pathways?

This project will not cover the needs of people with learning disabilities or people with learning disabilities and autism/ADHD, as the needs of these groups were included in the Cambridgeshire and Peterborough Learning Disability Needs Assessment and are a focus of the local Learning Disability Long-term Improvement Programme.

Structure

The structure of this chapter is outlined below:

Figure 1: Chapter outline



Key findings

- It is estimated that there are around:
  - 7,200 autistic people and 22,500 people with ADHD living in Cambridgeshire.
  - 2,350 autistic people and 7,550 people with ADHD living in Peterborough.
  - Many people have multiple neurodevelopmental conditions, with the co-occurrence between autism and ADHD estimated to fall between 20 to 70% (Rosello *et al.*, 2022).

- There have been a range of local reports involving people with lived experience, which show that autistic people and people with ADHD can face long waiting lists for diagnostic assessments, barriers to accessing mental healthcare and difficulties navigating health services.
- There are high rates of mental health conditions among autistic people and people with ADHD, including anxiety and depression, as well as eating disorders, self-harm and bipolar disorder (Katzman et al., 2017; Lai, 2023). These groups are also more likely to die by suicide, compared to their peers.
- Autistic people and people with ADHD are more likely to experience determinants of poor mental health, such as unemployment and homelessness, as well as facing stigma around autism/ADHD.
- Both nationally and in Cambridgeshire and Peterborough, there is increasing demand for autism and ADHD assessment services across all age groups. On top of this, referrals to some services were paused at the start of the COVID-19 pandemic. This has led to a substantial increase in waiting times for these services.
- National and local research shows that autistic people and people with ADHD report facing barriers to accessing mental health support (Price et al., 2020; Brede et al., 2022). Some autistic people and people with ADHD are unable to access effective mental healthcare, which can result in high levels of high levels of unmet mental health needs (Bitter et al., 2019; NHS England, 2023c).
- A survey of mental health services in Cambridgeshire and Peterborough identified strengths and gaps in the provision of support for autistic people and people with ADHD, with the greatest areas for improvement identified as the physical environment of buildings, support for family and friends and cross-system working.
- Although we have limited data about how many autistic people and people with ADHD access mental health services in Cambridgeshire and Peterborough, literature suggests that these groups are overrepresented and make up a significant proportion of people currently using mental health services.

Contents

Introduction

National research shows that both autistic people and people with ADHD are more likely to experience mental ill-health than the general population (Katzman et al., 2017; Lai, 2023), and report facing barriers to accessing mental health support (Price et al., 2020; Brede et al., 2022). Some autistic people and people with ADHD are unable to access effective mental healthcare, which can result in high levels of unmet mental health needs, poor outcomes, and in some cases, long stays in inpatient metal health settings (Bitter et al., 2019; NHS England, 2023c). The COVID-19 pandemic has slowed progress towards ensuring that all autistic people and people with ADHD are able to access the support they need to live full and happy lives (DHSC, 2021b; Behrmann et al., 2022).

This chapter of the mental health needs assessment will explore mental health needs and care for autistic people and people with ADHD, including access to diagnostic assessments for ADHD and autism; and access, experience and outcomes from mental health services.

Definitions

Autistic people and people with ADHD highlight that the language used to describe them is important (Kenny et al., 2016; AADPA, 2022). This is reflected in national NHS guidance, which states that:

> *'The terms used to communicate with, and about, autistic people can have a profound impact on people's attitudes towards autistic people. Healthcare professionals should be mindful that the terms they use to refer to autism conveys powerful messages about their attitudes toward autistic people. Certain terminology is considered unacceptable by some autistic people and, if used, may result in some people lacking faith in a professional or disengaging from a service. Terminology should describe autism in diagnostic, but not in excessively negative or deficit-based ways, for example, autism should not be referred to as a disease or illness.'* (NHS England, 2023c)

In this chapter, we have used identity first language, describing to 'autistic people' rather than 'people with autism', as this is often preferred (Kenny *et al.*, 2016) and is recommended by NHS England. Some people may also prefer to describe themselves as ADHD, being an ADHDer, or being an AuADHDer (being both autistic and ADHD). However, we recognise the right of individuals to determine how they would like to be described.

Autism

Autism 'describes the way some people communicate and perceive the world around them' (Autistica, 2024b). Although each autistic person is different, there are some behaviours associated with autism such as (Autistica, 2024b):

- Communicating differently to non-autistic people (e.g. differences in eye contact)
- Experiencing sensory differences (e.g. having decreased or increased sensitivity to sound and touch)
- Having a strong preference for routine, sameness or certainty
- Enjoying focused, more intense interests

Autism impacts people across their whole lives. However, the features of autism in individuals can change over time, from childhood to later adulthood, and in different contexts (Lord *et al.*, 2022).

ADHD

ADHD (attention deficit hyperactivity disorder) is a condition characterised by regulating concentration and attention, restlessness and impulsive behaviour. Not everyone with ADHD has all of these traits: the NHS estimates that between 2 to 3 in 10 people with ADHD have problems with concentrating and focusing, but not with hyperactivity or impulsiveness (NHS, 2021). ADHD can be a lifelong condition (NHS, 2021), and although some people are diagnosed as children, others are diagnosed later in life.

Neurodiversity

Neurodiversity is the 'natural variability within human brains and minds' (Lord *et al.*, 2022). This concept was developed by autistic activists and has been used to advocate for the rights of autistic people and people with ADHD, as well as those with other conditions such as Tourette's syndrome, dyslexia and dyspraxia. Neurodiversity focuses on recognising the strengths of neurodivergent people, instead of medical models that are often based around deficits or impairments.

SEND

SEND (special educational needs and disabilities) are needs and disabilities that impact children or young people's ability to learn. This can include ADHD, autism, dyslexia, dyspraxia and other conditions (UK Government, 2024). For example, a child with ADHD may find it difficult to regulate their concentration, which could impact their ability to learn in a standard classroom setting. Some children and young people with ADHD and/or autism are eligible for SEND support in school or an EHC (Education, Health and Care plan).

National policy

There are several national policies which are relevant to understanding the mental health needs of autistic people and people with ADHD.

The Autism Act (2009) states that local authorities, the NHS and integrated care boards (ICBs) have a duty to provide relevant services for the identification, diagnosis, needs assessment and support of autistic adults. This Act states that there should be a national strategy for autistic children, young people and adults. The latest strategy (2021 – 2026) set out 6 key areas which would make significant impacts on autistic people's lives:

- improving understanding and acceptance of autism within society
- improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- supporting more autistic people into employment
- tackling health and care inequalities for autistic people
- building the right support in the community and supporting people in inpatient care
- improving support within the criminal and youth justice systems

The NHS Long Term Plan (2019) set out to improve the health and wellbeing of autistic people by:

- Tackling the causes of preventable deaths amongst autistic people, such as by piloting the introduction of a specific physical health check (which may include physical as well as mental health)
- Improving the understanding of the needs of autistic people across the NHS, including through the introduction of a 'digital flag' that lets staff know when someone is autistic and making sure that all healthcare providers make reasonable adjustments
- Reduce waiting times for autism assessment services
- Reducing the numbers of autistic children, young people and adults in inpatient care
- Increasing investment in intensive, crisis and forensic services

These strategies have been supplemented by a 5 year autism research strategy (2022 – 2027), which sets out actions for the NHS to provide better evidence-based healthcare for autistic people. In 2023, NHS England produced guidance for integrated care boards and wider system partners around meeting the needs of autistic adults in mental health services; and the national Suicide Prevention Strategy (2023 – 2028) was published, which included autistic people as a priority group that may require targeted support in suicide prevention approaches.

NHS England has recently announced the formation of an ADHD taskforce, to investigate ADHD service provision and the experiences of people with ADHD.

Local policy

The Cambridgeshire and Peterborough All-age Autism Needs Assessment (2020) estimated the number of autistic people in Cambridgeshire and Peterborough, described their health and education needs and mapped local service

provision. This was used to inform the Cambridgeshire and Peterborough All-age Autism Strategy (2021 – 2026), which aims to ensure that Cambridgeshire and Peterborough is an 'autism friendly place' where autistic children and adults 'can live full, healthy and rewarding lives, within a society that accepts and understands them'. This strategy set out 8 key priorities around:

- Early intervention
- Awareness raising and training
- Employment and independence
- Housing
- Criminal justice system
- Joint commissioning of services
- Access to healthcare
- Diagnostic pathways

An All-age Autism Strategy Implementation Programme was launched at the start of 2024 to undertake cross-cutting priority improvements that build on the ambitions laid out in the 2021 Strategy whilst also responding to the current context, with all actions designed and agreed through collaboration with stakeholders. Throughout spring 2024, work was undertaken to map current autism support and services and the information available to residents. Through widespread engagement with stakeholders from across the system, three priority areas were identified:

- Waiting lists (and support whilst waiting)
- Access to services
- Navigating services

Through further engagement with system stakeholders, as well as national guidance and best practice, 15 key improvements across children and adult services have been identified to be further explored:

Table 1: Key improvements for children and young people, and for adults, as identified in the All-age Autism Strategy Implementation Programme

Children and young people	Adults
1) Delivering clear local guidance on autism and ADHD assessments 2) Improving communication and signposting 3) Streamlining current neurodiversity pathways 4) Enhancing the holistic needs-led support offer 5) Enhancing support for staff working in early help and education 6) Implementing a tool to identify and support neurodiversity needs 7) Increasing joint working between services 8) Assessing opportunities to scale early identification and intervention initiatives	1) Delivering clear local guidance on autism and ADHD assessments 2) Improving communication and signposting 3) Extending CLASS quality improvement work 4) Expanding needs-led peer-to-peer support 5) Increasing training and support for staff in mainstream services on neurodiversity and reasonable adjustments 6) Improving access to mental health support offer for autistic adults 7) Improving links/ joint-working between autism and ADHD support and services

In June 2024, work is currently underway to further develop the detail behind the adults key improvements. For the children and young people key improvements, options are being developed for a new neurodiversity model, which would:

- build on existing good practice within the geography, including the important work of the VCSE sector and parent-carer forums.
- draw on new research, innovations and best practice nationally from systems such as Portsmouth, Cornwall and Bedfordshire, Luton and Milton Keynes.

- improve the provision of holistic, needs-led support for autistic / neurodiverse children and young people, and their families.
- reflect the system's ambition to better meet neurodiversity needs earlier, and the additional complexity of this age group, with more organisations involved in meeting their needs.

The Joint Cambridgeshire and Peterborough Suicide Prevention Strategy (2022 – 2025) highlights that autistic people may require a specific focus in suicide prevention, as autistic people are at a greater risk of dying by suicide and may face barriers in accessing mental healthcare.

Making SEND everybody's business (2019 – 2024) is the local strategy for children and young people (aged 0 – 25) with special educational needs and disabilities (SEND). It states that considering and providing for the needs of children and young people with SEND should be 'everybody's business'.

There are no local strategies specifically focusing on ADHD.

Additional Resources

- Autism: Overview of policy and services and The Autism Act, 10 Years On
- Autism myths and causes
- ADHD in adults
- Talking about ADHD

What do local people tell us?

Over the last 5 years, multiple reports and workshops in Cambridgeshire and Peterborough have recorded the voices of autistic people and people with ADHD. Mental health has arisen as a consistent theme, as summarised in the diagram and table below.

Long waiting lists for diagnostic assessments

- Struggling to be referred to get a diagnosis
- Long waits can have a **negative impact on people's mental** health
- **Lack of support** when waiting to be assessed
- Need for more **post-diagnostic support**, including for those diagnosed privately

Barriers to accessing mental healthcare

- Autistic people report having their referrals to mental health teams and other forms of support **rejected due to 'complexity'**. A lack of alternative mental health provision leaves autistic people with **poorer access to mental healthcare**.
- When people are unable to access mental health support early on, they may **end up in mental health crisis** when this could have been avoided

Struggling to navigate health services

- **Lack of training** for healthcare professionals around autism, ADHD and SEND
- Struggling to navigate a **complex health system**
- **Inaccessible** of mental health services (e.g. struggling to arrange appointments)

There are some gaps in these reports: for example, we do not currently have a good understanding of the underlying reasons why people face barriers to accessing mental healthcare or whether these barriers are the same for every service. There are also limited local reports looking into the experiences of people from different ethnic backgrounds and people in contact with the criminal justice system. Full details of each report that was used in the summary diagram are listed in the table below:

Project	Description	What were the main findings?

All-age Autism Strategy Implementation (2024)	Workshops involving parent support groups, advocates, and colleagues from health, social care and education.	Whilst these workshops did not focus on mental healthcare, it was raised that: • There is increasing demand for autism assessments, which has led to long waiting lists. There are opportunities to increase early support and to provide more information for individuals seeking assessment to ensure that they understand the options available to them. • People reported facing barriers to accessing mental healthcare. Difficulty accessing services early could result in some people experiencing crisis when this could have been avoided through earlier intervention. o People reported that referrals to mental health services could be rejected due to 'complexity' or because they were waiting for an autism assessment. Some people reported being told that certain types of treatment (e.g. cognitive behavioural therapy) were not suitable for autistic people. A lack of alternative provision could leave autistic people with poorer access to care than non-autistic people. o People stated that there needs to be greater understanding of autism and reasonable adjustments within mainstream mental health services: particularly around autism as a lifelong condition and that a sudden deterioration in presentation could result from a mental health need. o A lack of speech and language therapy in mainstream mental health services could leave a gap in lower-level mental health support for autistic adults with selective mutism. • People report that it can be a complex landscape for individuals, families and carers to navigate different types of support services. For example, young adults may be supported in CAMHS, but when they move to adult services there are higher thresholds for accessing care.
PINPOINT Annual Survey 2023/24	The survey had 214 responses from parents and carers of children and young people.	Feedback from parents included: • Struggling to navigate a complex system of support, and that everything can be feel like a 'constant battle' with the onus on them. For example, one parent carer said '*waiting lists are too long. Won't give son a diagnosis of ADHD until his anxiety is dealt with, but can't offer us any support on that any time soon. The system is broken'.* • Feeling that health services are difficult to access and that they feel they are 'abandoned' after their child has received a diagnosis of a neurodevelopmental condition. • Views that thresholds for mental health services are too high, and that waiting lists are too long, which can exacerbate poor school attendance for children who are unable to attend due to poor mental health. • Reporting a lack of post-16 support services. • Feeling that professionals do not have enough training, knowledge and understanding around SEND, particularly in schools.
SUN Network (2023, 2024)	The SUN Network collects feedback from people who have experienced mental health challenges	The length of the waiting lists for ADHD and autism assessments is a consistently raised in feedback to the SUN Network (Sidney, 2023, 2024). In October 2023, the SUN Network also reported emerging issues around (Sidney, 2023): • Increasing numbers of people feeling frustrated about how to get onto a pathway for ADHD and autism assessment, not realising it is through their GP. • People reporting struggling with long wait times for assessments, and a lack of support whilst waiting. • People trying to go private for assessments if they can afford it, but not getting any further support after diagnosis if they chose this route.
Family Voice Peterborough's report on Health	Views gathered from multiple sources from 50 parents/carers of	Parent/carers who answered these surveys had children with SEND, with needs including autism, ADHD, global developmental delay and learning disabilities. Four key concerns were raised by parent carers: • Long waiting times for assessment and support

Inequalities (2023)	children with SEND.	• Lack of awareness around SEND, particularly in general practice and Accident and Emergency • Feeling that they were not listened to by healthcare professionals • Lack of reasonable adjustments being made in healthcare appointments
LGBTQ+ youth & mental health in Cambridgeshire and Peterborough (2022)	The Kite Trust interviewed 16 LGBTQ+ young people, aged 13 – 25	Although this report focused on LGBTQ+ young people's experiences of accessing, or trying to access mental health support, many young people raised that they faced specific barriers to accessing support due to being neurodivergent. These barriers included: • Discriminatory views of neurodivergence • Assumptions that mental health difficulties were due to neurodivergence • Problems believing that young people could be both autistic and trans • Difficulties accessing mental health services (e.g. trying to arrange appointments) • Lack of LGBTQ+ spaces for disabled people
Autistic Voices: local people's health and care experiences (2021)	13 autistic people and carers shared their experiences with Healthwatch	• People raised they found it hard to access an autism diagnosis and that waiting times were too long. • People felt that healthcare professionals and wider society need to better understand autism, especially autism in women and girls. • People raised that they would like clear information about autism, local services and support. They also stated that there is a need for more support, including help coming to terms with an autism diagnosis, and advice on employment and benefits. • People wanted better and easier access to support services, including being able to communicate via email and text. • People felt that mental health services should have a good understanding of autism and the needs of autistic people, so that reasonably adjusted and effective care is always provided. For example, some people reported being told they were 'too complex' to access some services and struggled to find an alternative type of support.

Cambridgeshire and Peterborough All-Age Autism Needs Assessment (2020)	The CCG collected experiences of autistic adults and worked with PINPOINT and Family Voice to gathers the experiences of children, young people and carers.	• Adults raised issues around long waits to access autism assessments, a lack of post-diagnostic support and the need to travel to London to access specialist interventions.
		• Children, young people and carers raised that:
		  o They felt it can be more difficult for girls to get an autism diagnosis than boys.
		  o There was a lack of post-diagnostic support, with someone reporting being 'given a diagnosis with no explanation as to what it means'.
		  o There were long waiting lists for parenting support.
		  o Trying to access support can be difficult, with one person stating that there a 'too many' professionals involved in 'complicated' EHCP processes.
		• It was reported that autistic children and young people who had adversity in early life were not always being accepted for multi-agency support, as their needs were attributed to their early life events. This could be a barrier to them accessing autism services and mental healthcare.
		• Stakeholders felt there is a need for support services for autistic children and young people that help them thrive and prevent them developing mental health conditions.

Local population

How many people are autistic and/or ADHD?

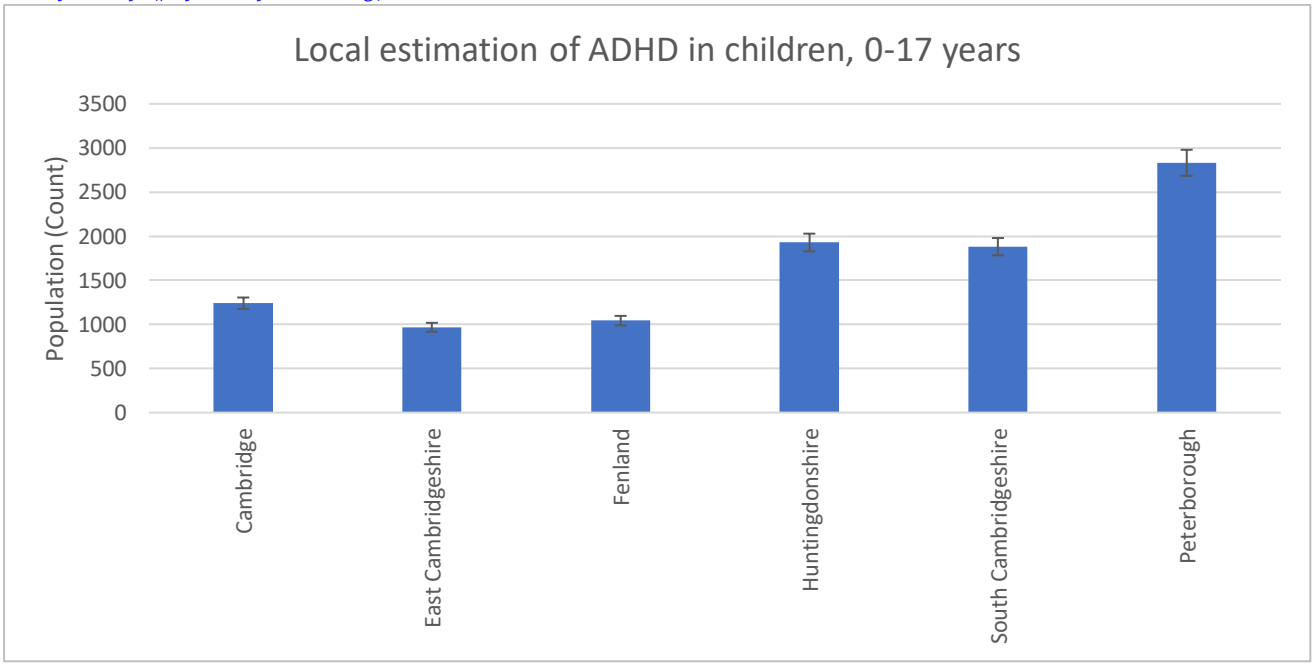
- Around 1% of people across all ages are autistic (Roman-Urrestarazu *et al.*, 2021a). 5% of children, and 3 to 4% of adults, are thought to have ADHD (NICE, 2023).

- The co-occurrence between autism and ADHD estimated to fall between 20 to 70% (Rosello *et al.*, 2022). Other neurodevelopmental conditions, such as dyspraxia, are also more common among people who are autistic or have ADHD (Cleaton and Kirby, 2018; Royal College of Psychiatrists, 2020a).
- It is estimated that:
    - There are around 7,200 autistic people and 22,500 people with ADHD living in Cambridgeshire.
    - There are around 2,350 autistic people and 7,550 people with ADHD living in Peterborough.
- ADHD and autism are both highly heritable (Larsson *et al.*, 2014; Tick *et al.*, 2016), hence it is not uncommon that multiple people within the same family have autism and/or ADHD.

ADHD

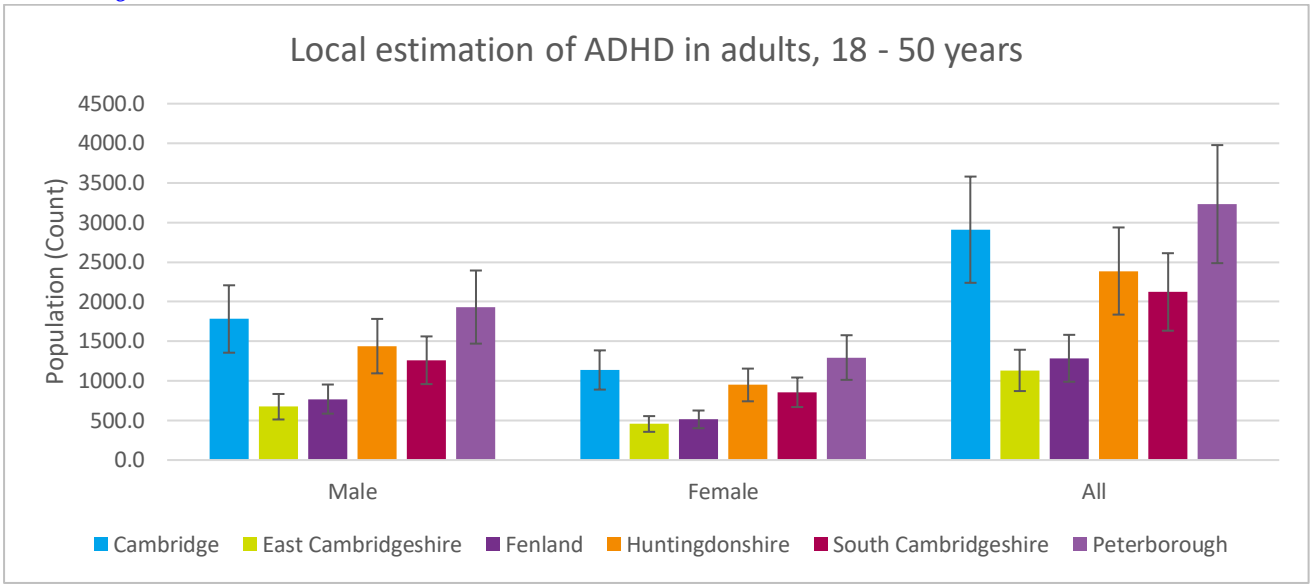
Reviews of international literature suggest that 5.29% of children and young people (under 18s) have ADHD (Polanczyk *et al.*, 2007). Using this figure, it is estimated that 7,050 under 18s in Cambridgeshire, and 2,850 in Peterborough, have ADHD.

Figure 2: Estimated number of children and young people (aged 0 – 17) with ADHD, Cambridgeshire and Peterborough. Data sources: The Worldwide Prevalence of ADHD: A Systematic Review and Metaregression Analysis | American Journal of Psychiatry (psychiatryonline.org), ONS Census 2021



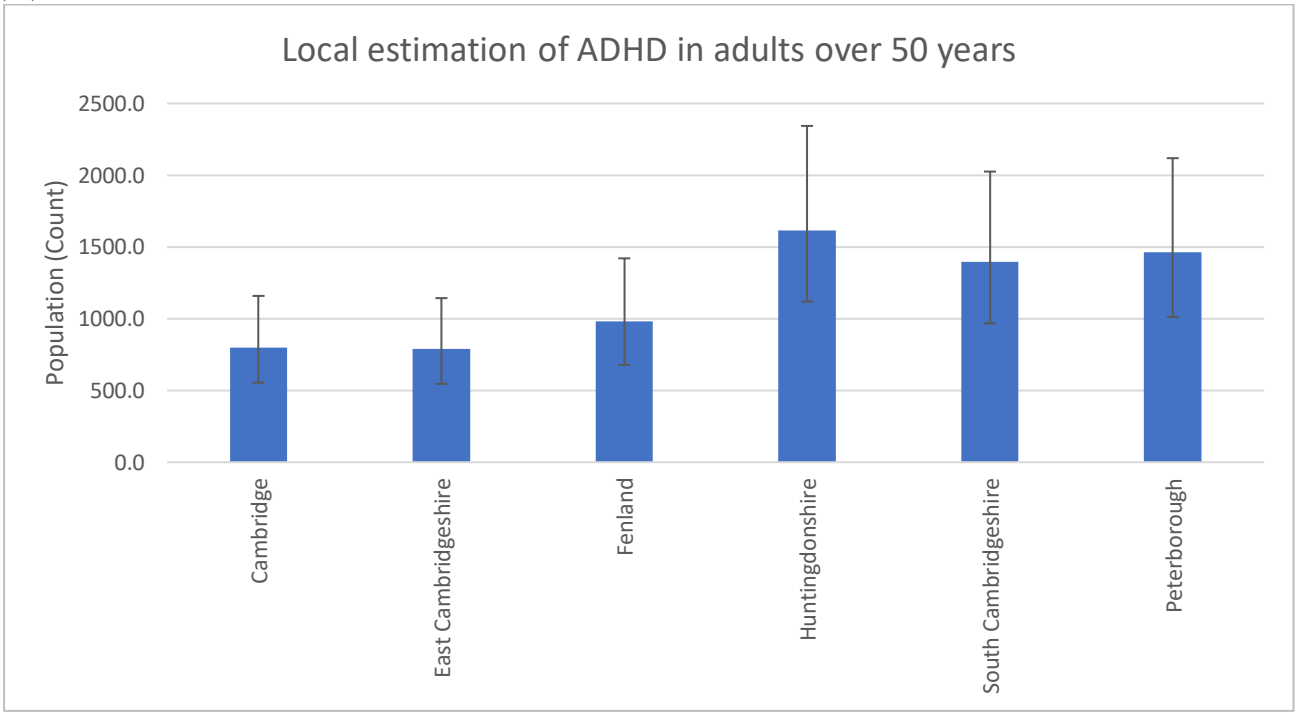
It is estimated that around 9,850 adults (aged 18 – 50) in Cambridgeshire have ADHD (5,900 males and 3,900 females) and 3,250 adults in Peterborough have ADHD (1,950 males and 1,300 females).

Figure 3: Estimated of adults (aged 18 – 50) with ADHD, Cambridgeshire and Peterborough. Data sources: Cross-national prevalence and correlates of adult attention-deficit hyperactivity disorder | The British Journal of Psychiatry | Cambridge Core, ONS Census 2021



Local estimates for ADHD in the 50+ age group are about 5,600 adults in Cambridgeshire and 1,450 adults in Peterborough.

Figure 4: Estimated of adults (aged 50+) with ADHD, Cambridgeshire and Peterborough. Data sources: Prevalence of attention-deficit/hyperactivity disorder in older adults: A systematic review and meta-analysis and ONS Census 2021 population



For information about how ADHD prevalence was calculated, please refer to the appendix.

Autism

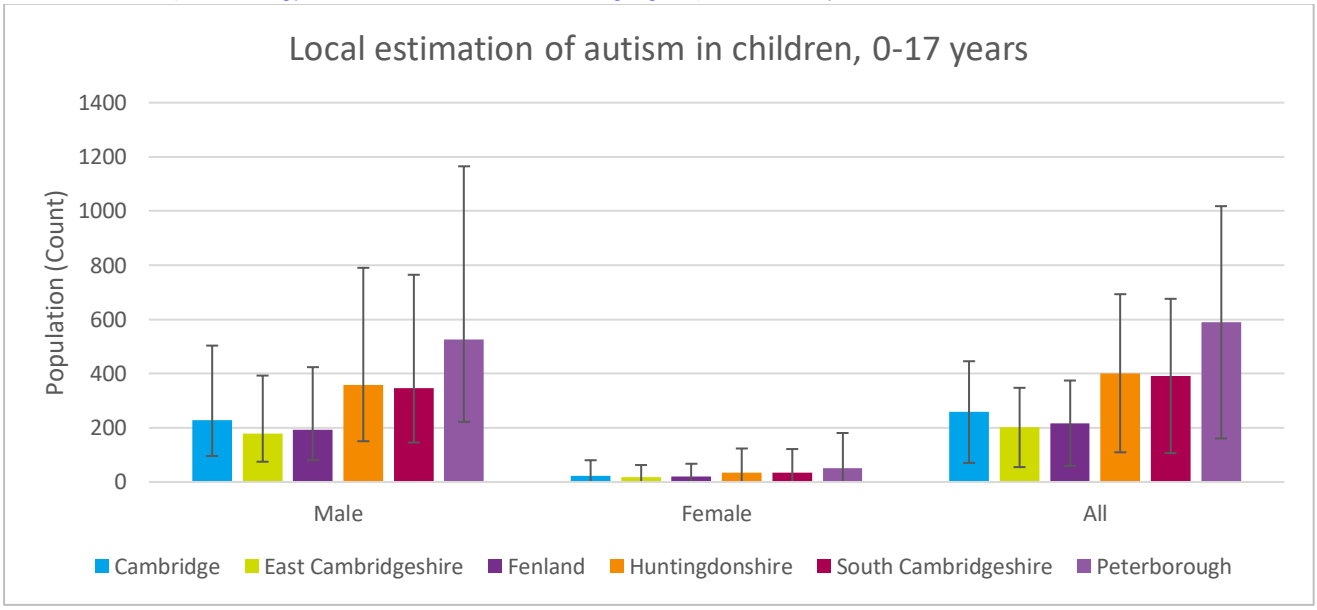
- It is estimated that 1.1% of the population is autistic (95% confidence interval 0.3% - 1.9%) (Brugha *et al.*, 2016). Using these figures and population data, we can estimate that:
    - There are around 7,200 autistic people living in Cambridgeshire.

  - There are around 2,350 autistic people living in Peterborough.
- Estimated rates of autism are significantly higher in men (1.9%) than women (0.2%). However, it has been suggested that assessments for autism may draw more on how the condition manifests in men, and this may lead to under identification of autism in women (Brugha *et al.*, 2016).
- In the school year 2022/23, there were 1,749 children in Cambridgeshire, and 1,064 in Peterborough, who had autism as a recognised special education need.
- It is estimated that the number of autistic older adults (aged 65+) will increase substantially by 2040, by 32% in Cambridgeshire and 42% in Peterborough, due to the ageing population.

Estimated prevalence

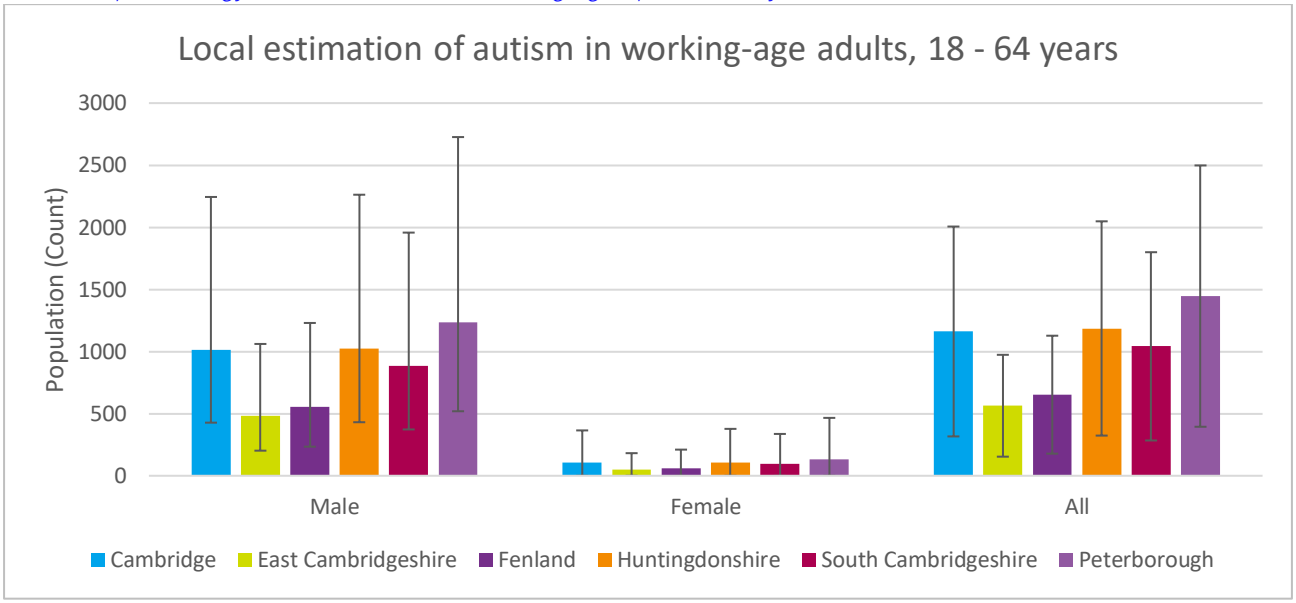
It is estimated that there are 1450 autistic children and young people (aged 0 – 17) in Cambridgeshire and 600 in Peterborough.

Figure 5: Estimated number of autistic children and young people (0 – 17 years), Cambridgeshire and Peterborough. Data sources: Epidemiology of autism in adults across age groups and ability levels and ONS Census 2021



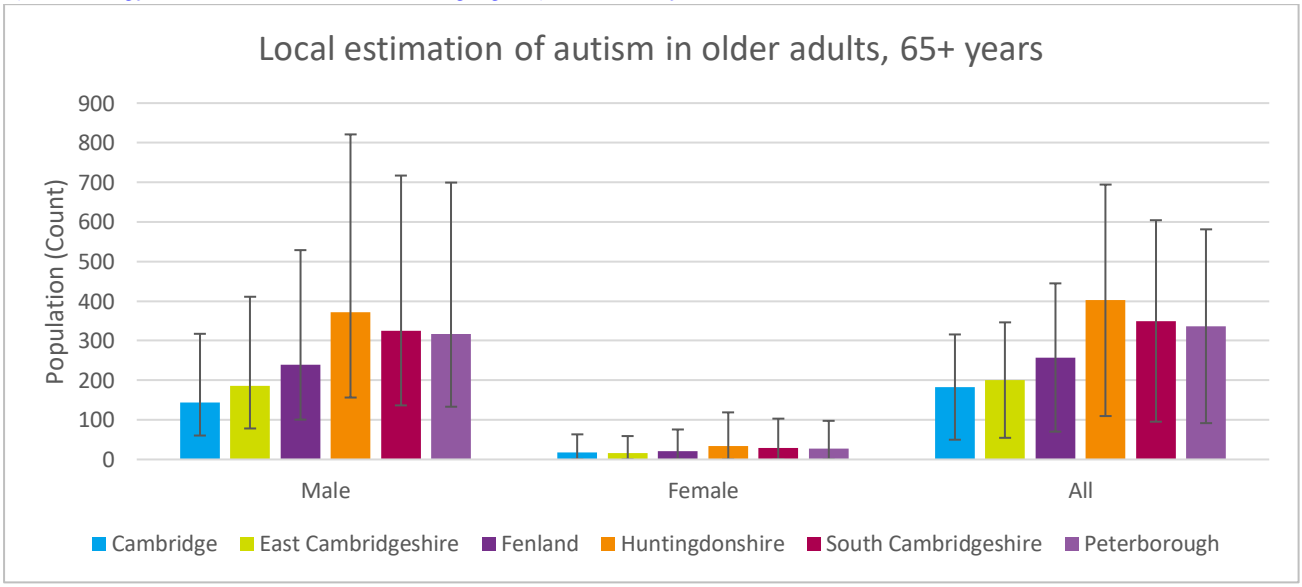
It is estimated that there are 4350 autistic working-age adults in Cambridgeshire (aged 18 – 64) and 1400 in Peterborough.

Figure 6: Estimated number of working-age autistic adults (18 – 64 years), Cambridgeshire and Peterborough. Data sources: Epidemiology of autism in adults across age groups and ability levels and ONS Census 2021



It is estimated that there are 1400 autistic older adults in Cambridgeshire (aged 65+) and 350 in Peterborough.

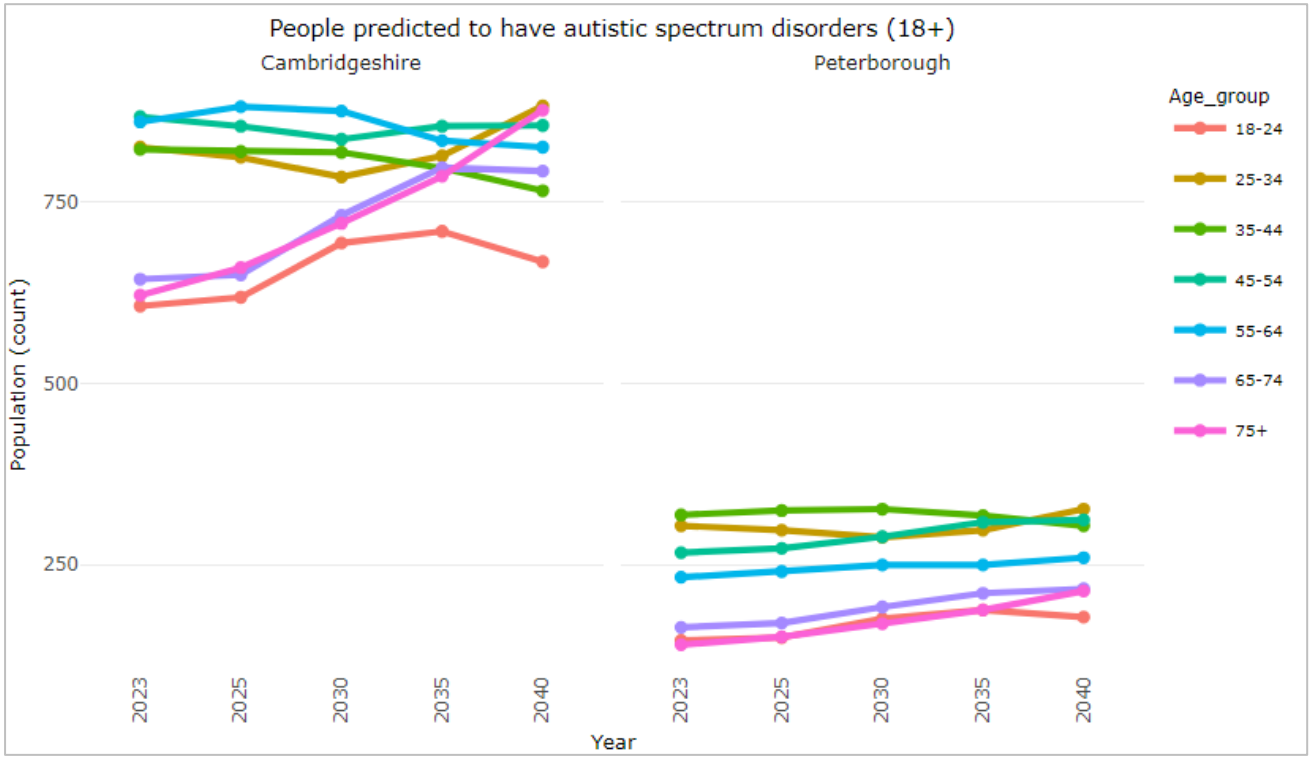
Figure 7: Estimated number of older autistic adults (65+ years), Cambridgeshire and Peterborough. Data sources: Epidemiology of autism in adults across age groups and ability levels and ONS Census 2021



Projections

In Cambridgeshire and Peterborough, the number of autistic people is predicted to substantially increase by 2040, particularly in the 65+ age group. In 2040, the number of people aged 65+ predicted to be autistic will increase by about 32% in Cambridgeshire and 42% in Peterborough compared to 2023. This is due to the increasing numbers of older adults in Cambridgeshire and Peterborough, rather than increasing prevalence.

Figure 8: Projected autism population, Cambridgeshire and Peterborough, 2023 – 2024. Data source: Projecting Adult Needs and Service Information System, Projecting Older People Population Information System



Note: The prevalence rates have been applied to ONS population projections to give estimated numbers of people predicted to be autistic to 2040.

Rate of diagnosis

In Cambridgeshire and Peterborough, there is a much higher proportion of children and young people with an autism diagnosis on their healthcare records, compared to adults and older adults. This trend is also seen nationally.

Table 2: Proportion of people with an autism diagnosis on their healthcare records by age group, 2024. Data source: Population and Person Insight (PaPI) dashboard

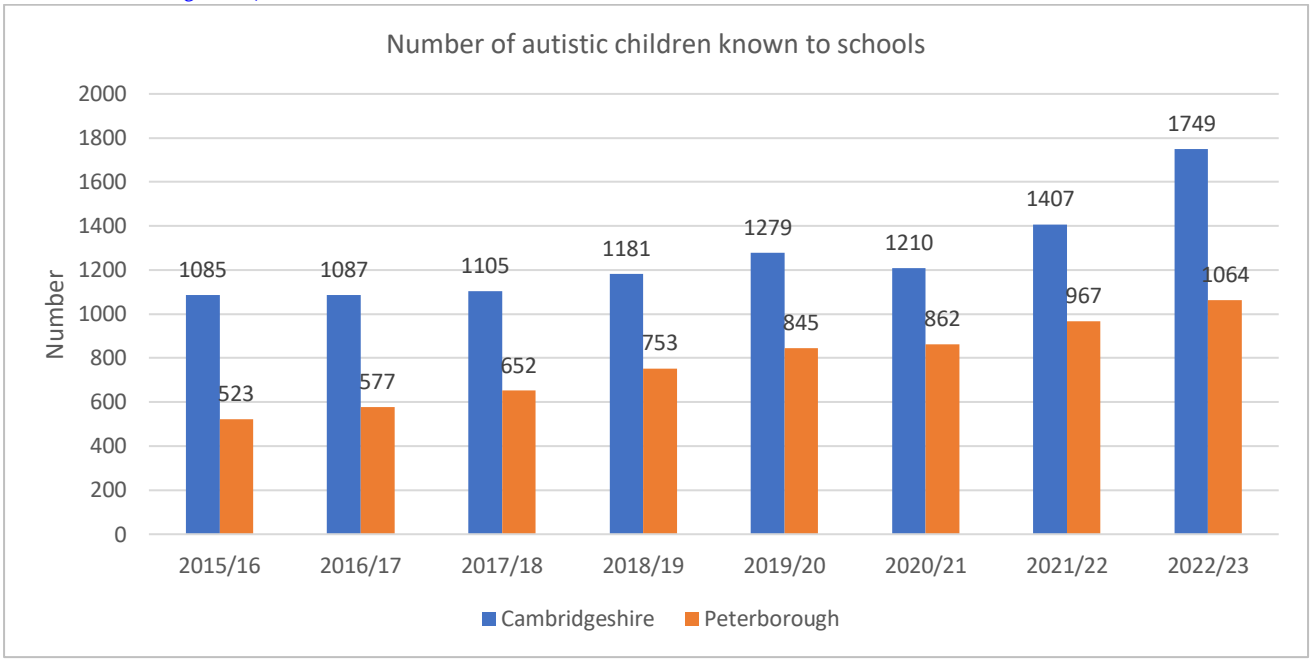
	Proportion with autism diagnosis	
Age group	Cambridgeshire and Peterborough	England
0 – 17	0.7%	0.8%
18 – 64	0.3%	0.3%
65+	0.1%	0.1%

Data analytics for the Population and Person Insight (PaPI) dashboard have been derived from a person-level clinical segmentation data model produced by OBH (Outcome Based Healthcare), using linked predominantly secondary care datasets held in the NCDR, covering people registered to a GP practice in England.

Autistic children and young people known to schools

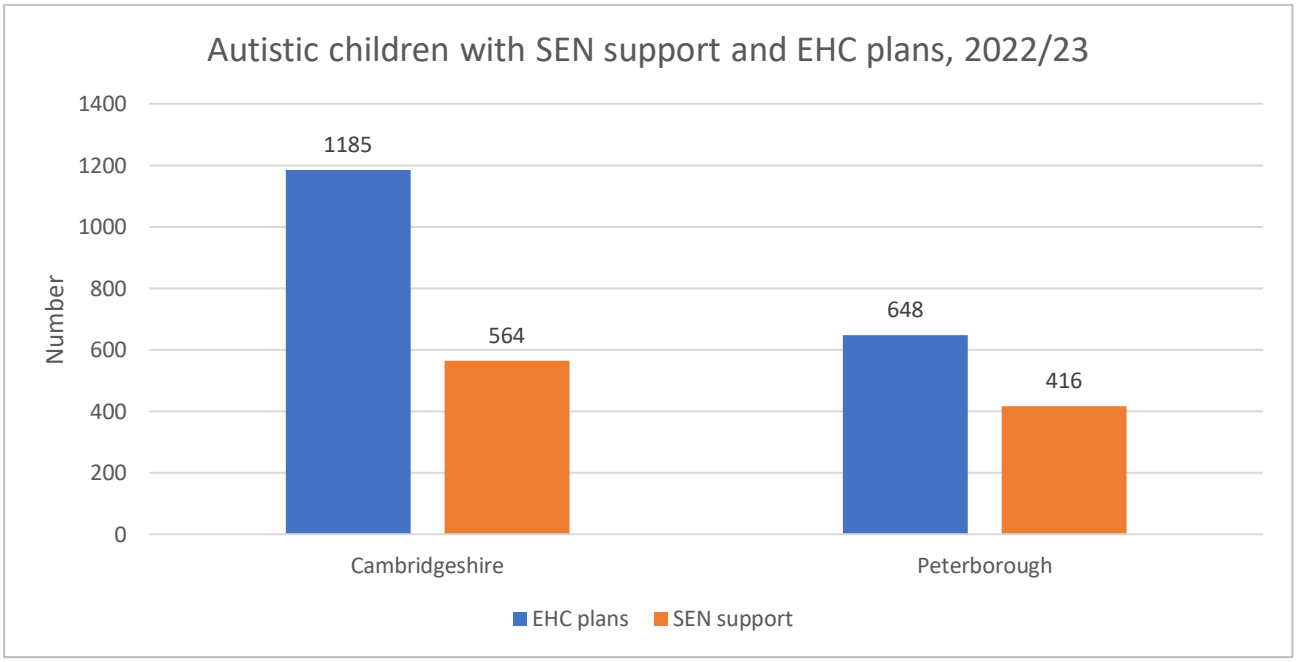
Between 2015/16 and 2022/23, the number of autistic children and young people known to schools increased by 61% in Cambridgeshire and a 103% in Peterborough. In the school year 2022/23, there were 1,749 children in Cambridgeshire, and 1,064 in Peterborough, who had autism as a recognised special education need. This is higher numbers than the estimated prevalence above.

Figure 9: Number of children with autistic spectrum disorder known to schools, 0-19 years. Data source: Special educational needs in England, Academic year 2022/23 – Explore education statistics – GOV.UK (explore-education-statistics.service.gov.uk), School census data



68% of autistic children known to schools in Cambridgeshire had Education and Health Care (EHC) plans and 32% had special education needs (SEN) support. 61% of autistic children known to schools in Peterborough had EHC plans and 39% received SEN support.

Figure 10: Autistic children with EHC plans and SEN support, 0-19 years. Data source: Special educational needs in England, Academic year 2022/23 – Explore education statistics – GOV.UK (explore-education-statistics.service.gov.uk), School census data



Prison population

Link to previous section of needs assessment:

- The prevalence of autism and ADHD amongst people in prison is likely to be substantially higher than in the general population, with estimates ranging from 20 to 50% [(Criminal Justice Joint Inspectorate,

2021b),(Rack, 2005)]. A review of evidence found there was a lack of reliable assessment of levels of neurodevelopmental conditions, and of the needs of specific sub-populations, at both a local and national level (Criminal Justice Joint Inspectorate, 2021b).

- People with ADHD in prison can face a range of barriers to accessing healthcare, including a lack of awareness of ADHD symptoms and treatment among prison staff, poor multiagency working between teams and limited preparation for prison release (Young *et al.*, 2018).
- Unmet needs relating to neurodivergence are likely to have a negative impact on factors which are important to mental health:
    - One survey of adult men prison found that those who had ADHD, autism or learning disabilities were over 3 times more likely to have been homeless before entering prison and over twice as likely to have been unemployed, compared to their peers. Over 80% had a previous conviction or had previously spent time in prison (Mccarthy et al., 2016).
    - Due to a lack of understanding around autism, autistic people in prison are at a higher risk of over-medicalisation, bullying, seclusion, and restraint (Durcan, 2020).
    - People leaving prison who take medication to manage their ADHD symptoms are 30% less likely to reoffend (Lichtenstein et al., 2012).
- Many neurodivergent people in prison are unable to access support, with one survey of people in contact with the criminal justice system finding that (User Voice, 2021):
    - Only 34% of had been screened for neurodevelopmental conditions.
    - 70% of people who were neurodivergent did not had any adjustments put in place to support their neurological needs.

University student population

There are around 12,000 students at Anglia Ruskin University and 24,000 students at the University of Cambridge, which are thought to make up 51% of the population in Cambridge City. Earlier sections of the needs assessment highlight that university students can face specific barriers to accessing mental healthcare.

There are also specific issues that can arise around autism and ADHD services relating to students:

- Some international students may have been given an ADHD diagnosis in another country. Without 'sufficient supporting evidence of a comprehensive diagnostic evidence', students may need to go through an ADHD assessment in the UK before being able to be prescribed ADHD medication. Students may not be aware what medical evidence they need to bring before starting university (Royal College of Psychiatrists in Scotland, 2023).
- Some educational psychologists may carry out assessments for ADHD, to support people to access reasonable adjustments in education settings. This is different to a full clinical diagnosis of ADHD, which considers how other factors (such as OCD, anxiety and trauma) may present as similar symptoms to ADHD. Only 'healthcare professionals with training and expertise in diagnosing and managing ADHD' can initiate ADHD medication (NICE, 2018).
- From April 2024, The Crane Fund, a source of financial support for University of Cambridge students who need healthcare that is not readily accessible under the NHS or university services, will no longer fund ADHD and autism assessments, or private medication (including ADHD medication) (University of Cambridge, 2024).
- Autism and ADHD services are only commissioned to deliver care for the population of people who have registered with Cambridgeshire GPs, however some students may remain registered with their home GPs.
- Accessing GPs remotely from a different residence can be an issue in the prescription of ADHD medication, as these are controlled drugs.
- Non-medical use of stimulant medication had been reported among university students (Faraone *et al.*, 2020).

It is important for services to consider the specific needs of university students. For example, there may be an increase in referrals for autism and ADHD assessments in September and October, when students access disability services.

How are autism and ADHD linked to mental health?

- ADHD and autism are not in themselves mental health conditions, but autistic people and people with ADHD are more likely to experience mental health conditions (Lai *et al.*, 2019; Choi *et al.*, 2022). The factors contributing to this are complex and can include the pressures of 'masking' or living in a world designed for neurotypical people (Cassidy *et al.*, 2018; Cook *et al.*, 2021). As a result, a whole system approach is required to improve the mental health and wellbeing of these population groups.
- There are higher rates of undiagnosed autism and ADHD amongst people seeking mental health interventions than in the general population (Wikramanayake *et al.*, 2018; Bitter *et al.*, 2019).
- Autistic people and people with ADHD can experience diagnostic overshadowing in mental health services. This is when traits of a neurodevelopmental condition are misattributed to a mental health condition; or when mental health symptoms are misattributed to a neurodevelopmental condition (NHS England, 2023c). This may mean that people do not receive autism or ADHD assessments, or appropriate mental health treatment.
- Understanding ADHD and autism is important to providing effective mental health interventions, with the Royal College of Psychiatrists stating that that 'therapies applied without awareness of the autism can be harmful or, at the least, ineffective' (Royal College of Psychiatrists, 2020a).

Autism, ADHD and trauma

- Autistic people and people with ADHD are more likely to experience adverse and traumatic events such as bullying and domestic abuse (Arrondo *et al.*, 2023; Trundle *et al.*, 2023).
- Some research suggests that are complex links between neurodevelopmental conditions and adverse childhood experiences (ACEs), but this relationship is not fully understood (Gajwani and Minnis, 2023).
- Guidance from the Royal College of Psychiatrists state that trauma-informed care is particularly important for autistic people and people with ADHD, as they often experience bullying and feel that they 'don't fit in' (Royal College of Psychiatrists, 2020b; The Royal College of Psychiatrists in Scotland, 2023).

Autism and mental health

Autistic people are more likely to develop mental health conditions than their non-autistic peers. Around 30% of autistic adults report being diagnosed with a mental health condition (NHS England, 2023c) and 80% meet the criteria for a mental health condition at some point in their life (Lever and Geurts, 2016). There is a particularly high prevalence of depression, with most studies finding that between 25 – 50% of autistic people experience depression (Ward, 2019).

Table 3: Pooled estimated prevalence of mental health conditions in autistic populations and the general population. Adapted from: Lai et al. 2019

Mental health conditions	Prevalence (95% confidence intervals)	
	Autistic population	General population
Anxiety disorders	20% (17 – 23%)	15% (11 – 19%)
Obsessive-compulsive disorder and related conditions	9% (7 – 10%)	0.7% (0.4 – 1.1%) #
Bipolar and related conditions	5% (3 – 6%)	0.71% (0.6 – 0.9%) for bipolar I 0.50% (0.4 – 0.6%) for bipolar II
Schizophrenia and psychotic disorders	4% (3 – 5%)	0.46% (0.4 – 0.5%)
Conduct disorders and related conditions	12% (10 – 15%)	8.9%#
Sleep-wake disorders (e.g. insomnia)	13% (9 –17%)	3.7%*

** prevalence for people aged 18 and under; # for over 18 years*

Other research highlights that:

- Some symptoms of mental ill-health can be different for autistic people, such as distress-related behaviours such as stimming, social withdrawal and sleep problems becoming more obvious (Autistica, 2024a).
- Autistic people can experience 'burnout', which they describe as 'chronic exhaustion, loss of skills, and reduced tolerance to stimulus', as a result of the cumulative burden of life stress (e.g. masking, life transitions) and inability to obtain support (Raymaker *et al.*, 2020).
- Autistic children and adults are more likely to self-harm than their non-autistic peers (Steenfeldt-Kristensen, Jones and Richards, 2020a; Blanchard *et al.*, 2021), with one meta-analysis suggesting that the prevalence of self-injury amongst autistic people (all-age) is 42% (Steenfeldt-Kristensen, Jones and Richards, 2020b).
- Autistic people die on average 16 years than earlier than the general population, in part due to a higher rate of suicide (Hirvikoski *et al.*, 2016). One study suggests that at least 10% of people who die by suicide are autistic (Cassidy *et al.*, 2022). The risk of suicide is particularly high for autistic women, who are 13 times more likely than non-autistic women to die by suicide (NHS England, 2023c).
- Research about rates of substance use amongst autistic people is mixed (Ressel *et al.*, 2020), although one study suggests that drug use can sometimes stem from wanting to mask autistic traits and self-medicating mental health symptoms (Weir, Allison and Baron-Cohen, 2021).
- Autistic people are more likely to report that they have been misdiagnosed with a mental illness than non-autistic people (Au-Yeung *et al.*, 2019), an issue that seems to be particularly common amongst autistic women (Royal College of Psychiatrists, 2020a).
- Some research suggests that the COVID-19 pandemic was associated with poorer mental health for autistic people, although some people reported positive impacts of lockdowns (Scheeren *et al.*, 2023).
- There is limited research into the prevalence of mental health conditions amongst autistic people who have extensive support needs (for example, autistic people with complex physical health needs or who are minimally speaking) (Lai, 2023).

A review of studies found that anxiety is a common experience among autistic children and young people (White *et al.*, 2009), with one small study of autistic children (aged 12 – 14) finding that 40% had anxiety disorders (Simonoff *et al.*, 2008). Another small study found that suicidal ideation or attempts was thought to be 28 times higher in autistic children, compared to non-autistic children (Mayes *et al.*, 2013).

Overrepresentation in mental health services

There are high rates of high rates of undiagnosed autism among people seeking mental healthcare. For example, around 1 in 5 women with anorexia in eating disorder services are autistic (Autistica, 2019a) and studies suggest that there are high rates of autism amongst young people with avoidant/restrictive food intake disorder (ARFID) (Sanchez-Cerezo *et al.*, 2023).

Up to 10% of adults in inpatient mental health services are autistic, compared to just 1% of the general population (Harper *et al.*, 2019). Autistic women are 5.6 times more likely, and autistic men 3.8 times more likely, to spend time in a mental health inpatient setting than their non-autistic peers (Martini *et al.*, 2022).

Why are there higher rates of mental ill-health amongst autistic people?

Many different factors may contribute to autistic people being more likely to experience mental ill-health:

- Some evidence shows autistic people are more likely to experience wider determinants that are associated with poor mental health, such as being bullied, unemployed and socially isolated (Hedley *et al.*, 2018; Griffiths *et al.*, 2019). However, research involving people diagnosed with autism in adulthood, who were employed and living independently, still found 'strikingly high' rates of anxiety and depression (Gotham *et al.*, 2015).
- Research involving autistic people shows that 'masking' (camouflaging or hiding the characteristics associated with autism) is associated with psychological distress (Cook *et al.*, 2021) and suicidal ideation (Cassidy *et al.*, 2018).

- Other evidence suggests that cognitive, emotional and sensory factors associated with autism may contribute. For example, autistic people are more likely to experience higher levels of 'intolerance of uncertainty', which is linked to anxiety (Jenkinson, Milne and Thompson, 2020).

Local data

These analyses use data form PaPI (the Population and Person Insight dashboard) and are based on diagnoses of autism and other conditions in healthcare records. True prevalence is likely to vary, for example many autistic people do not have a clinical diagnosis (O'Nions et al., 2023).

Depression and severe mental illness

In Cambridgeshire and Peterborough, people with an autism diagnosis are many times more likely to have a recorded depression or severe mental illness (SMI) diagnosis (as defined by NHS England), compared to the general population. This is true across all age groups: for example, autistic children (aged 0 – 17) were 8 times more likely to have a recorded depression diagnosis; and autistic adults (aged 18+) were over 12 times more likely to have a recorded SMI.

Table 4: Prevalence of depression and severe mental illness (SMI) in autistic population and the general population, Cambridgeshire and Peterborough ICB. Data source: Population and Person Insight dashboard

	Depression prevalence			SMI prevalence		
Age group	Autistic population	General population	Rate	Autistic population	General population	Rate
0 - 17	2.4%	0.3%	x8.0	0.7%	0.0%	-
18 - 64	36.3%	10.2%	x3.6	13.8%	1.1%	x12.5
65+	35.7%	8.4%	x4.3	22.4%	1.2%	x18.7

Co-occurring conditions

The most common co-occurring conditions among autistic children and young people in Cambridgeshire and Peterborough are asthma (4.6 times more common than in the general population), learning disability (20 times more common) and epilepsy (19.4 times more common).

Table 5: Prevalence of co-occurring conditions in children and young people in Cambridgeshire and Peterborough

Top 5 co-occurring conditions (autistic population, 0 - 17 years)	Autistic population	General population
Asthma	14.7%	3.2%
Epilepsy	9.7%	0.5%
Learning disability	6.0%	0.3%
Physical disability	4.1%	0.5%
Depression	2.4%	0.3%

The most common co-occurring conditions among autistic working-age adults in Cambridgeshire and Peterborough are depression (3.6 times more common than in the general population), learning disability (54 times more common) and asthma (2.9 times more common).

Table 6: Prevalence of co-occurring conditions in working-age adults in Cambridgeshire and Peterborough

Top 5 co-occurring conditions (autistic population, 18 - 64 years)	Autistic population	General population
Depression	36.3%	10.2%
Learning disability	27.0%	0.5%
Asthma	19.5%	6.7%
Epilepsy	16.0%	0.8%
Serious mental illness	13.8%	1.1%

The most common co-occurring conditions among autistic older adults in Cambridgeshire and Peterborough are hypertension (1.4 times more common than in the general population), depression (4.3 times more common) and learning disability (163.5 times more common).

Table 7: Prevalence of co-occurring conditions in older adults in Cambridgeshire and Peterborough

Top 5 co-occurring conditions (autistic population, 65+ years)	Autistic population	General population
Hypertension	57.1%	42.2%
Depression	35.7%	8.4%
Learning disability	32.7%	0.2%
Diabetes	31.6%	18.2%
Coronary heart disease	24.5%	16.4%

Additional Resources

- Autism: Overview of policy and services
- Autistica's report Building Happier Healthier Longer Lives
- University students with attention deficit hyperactivity disorder (ADHD): a consensus statement from the UK Adult ADHD Network (UKAAN)
- Autism-friendly accreditation and a blog on Autism Accreditation in Prison

ADHD and mental health

There is comparatively less research looking at the links between ADHD and mental health conditions, despite early research indicating that there may be a stronger link between ADHD and mental ill-health than with autism (Hargitai *et al.*, 2023). Studies show that people with ADHD are more likely to develop mental health conditions across their lifetime than the general population, with as many as 80% of adults with ADHD experience at least one mental illness (Katzman *et al.*, 2017). Research has found that:

- Adults with ADHD are more likely to experience depression, bipolar disorder, 'personality disorders' and anxiety disorders than their peers who do not have ADHD (Choi *et al.*, 2022).
- Between 22 to 55% of people with ADHD report having sleep problems (Hvolby, 2015).
- There are higher rates of suicidal ideation, suicide attempts and deaths by suicide amongst people with ADHD (Balazs and Kereszteny, 2017).
- Eating disorders may be more common amongst people with ADHD than the general population, particularly bulimia and binge eating disorder (Nazar *et al.*, 2014).
- Symptoms of poor mental health can impact ADHD traits: for example, poor sleep may particularly effect on executive function for people with ADHD (Floros *et al.*, 2021). Some people with ADHD report experiencing 'burnout', which can make emotional regulation and directing attention more challenging than usual (Neff, 2024).
- Some research suggests that the COVID-19 pandemic was associated with poorer mental health for people with ADHD (Behrmann *et al.*, 2022). This was compounded by difficulties accessing support services at this time.

Reviews show that children and young people with ADHD are more likely to have oppositional defiant disorder, conduct disorder and to be diagnosed with 'antisocial personality disorder' than their peers (Sciberras, Roos and Efron, 2009). Some studies show that children with ADHD are more likely to experience anxiety and mood disorders, although other research has not found a significant association between ADHD and these conditions (Sciberras, Roos and Efron, 2009).

ADHD and substance use

A range of research highlights higher rates of 'substance use disorder' amongst adults with ADHD (Choi *et al.*, 2022), with one study finding that over 1 in 5 people with this condition have ADHD (van Emmerik-van Oortmerssen *et al.*, 2012). There may be a greater severity of substance use and poorer outcomes amongst adults who have ADHD, compared to the general population (Faraone *et al.*, 2007).

Overrepresentation in mental health services

There are relatively high rates of ADHD amongst people using mental health services (Gerhand and Saville, 2022), with surveys suggesting that between 17 to 22% of people receiving secondary mental healthcare, and 7% receiving inpatient mental health treatment, have ADHD (Bitter *et al.*, 2019; Asherson *et al.*, 2022).

One multinational European study found relatively high rates of ADHD among people receiving outpatient mental healthcare, particularly for people receiving treatment for substance use (Deberdt *et al.*, 2015).

Table 8: Prevalence of ADHD among people receiving outpatient mental healthcare for various mental health conditions. Data source: Deberdt et al. 2015

Treatment need	ADHD prevalence
Depression (n = 1215)	12.3%
Bipolar disorder (n = 268)	10.8%
Obsessive-compulsive disorder (n = 126)	13.5%
Anxiety disorders (n = 803)	15.8%
Eating disorders (n = 113)	21.2%
Substance use (n = 104)	30.8%
Alcohol use (n = 133)	27.1%

There is no research systemically assessing the rate of misdiagnosis of mental illnesses amongst adults with ADHD (Asherson et al., 2012).

ADHD and autism

There is limited research into the mental health needs of people with both ADHD and autism. Some studies suggest that co-occurring ADHD and autism is associated with a higher risk of anxiety, depression, schizophrenia and bipolar disorder, compared to people with solely autism or ADHD (Chen et al., 2015). Other studies suggest that children with ADHD and autism are more likely to experience depression, anxiety and behaviour or conduct problems, compared to those who solely had autism or ADHD (Casseus, Kim and Horton, 2023).

Local data: suicide and neurodivergence

- In Cambridgeshire and Peterborough, around 10% of individuals who died by suicide between 2019 and 2021 either had a clinical diagnosis, were pursuing a diagnosis, or believed by those around them to exhibit behaviours suggestive of neurodivergence (including autism, ADHD, dyslexia, dyspraxia and other conditions).
- Around 5% of people who died by suicide over this period were thought to be autistic; and 5% were thought to have ADHD. These figures include people both with and without a clinical diagnosis.

Wider determinants and inequalities

- Autistic people and people with ADHD may be more likely to experience determinants of poor mental health, in domains such as housing, employment and education.
- Autistic people and people with ADHD can face stigma and discrimination around these conditions, which is associated with poor mental wellbeing:

  - Stigma around ADHD is associated with poorer life satisfaction and mental wellbeing; as well as poorer adherence to ADHD medication (Mueller et al., 2012).
  - Stigma around autism is associated with poorer wellbeing and quality of life, and greater levels of psychological distress, for autistic people and their families (Turnock, Langley and Jones, 2022).
  - Stigma around autism can be experienced differently depending on other factors, such as ethnicity, gender and religion (Turnock, Langley and Jones, 2022), with autistic people reporting poor understanding of how different aspects of their identity can intersect (APPGA, 2019).
- Following a 'neurodiversity paradigm' promotes the acceptance of autism and ADHD and focuses attention on ending stigma and changing wider factors (such as unemployment) that impact of mental health of autistic people and people with ADHD (Pellicano and den Houting, 2022).

Wider determinants of health

The conditions in which we '*are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life*' are central to our mental health (World Health Organisation, 2022). The following table summarises data around wider determinants of health for people with ADHD and autistic people; and highlights the need for improvements in services and systems to better meet the needs of neurodivergent people.

The links in the table below are to earlier sections of the mental health needs assessment, which provide more detail about how these factors are important to mental health.

Factor	Evidence base
Socioeconomic deprivation	One study found that the rates of ADHD in children were twice as high in the most deprived areas of England, compared to the least deprived areas (Prasad et al., 2018). Reasons for this trend are unclear.
Poverty and financial insecurity	One large study involving English school children found that autism diagnoses were more likely among pupils eligible for free school meals, eligibility for which is based on family income (Roman-Urrestarazu et al., 2021b).
Housing, homelessness and environmental justice	There is evidence that neurodivergent people (including people with ADHD and autistic people) are more likely to become homeless and can face barriers to accessing housing support (Blood et al., 2023). A recent audit of the needs of people experiencing homelessness in Cambridgeshire and Peterborough found that (Hertzberg, 2024): • 26% reported having a learning disability. • 19% reported having been diagnosed with ADHD/ADD. • 11% reported having been diagnosed with autism.
Education and life-long learning	Autistic pupils are likely to have poorer experiences in school than their non-autistic peers. National surveys show that: • Only 26% of autistic pupils feel happy at school (National Autistic Society, 2023); • Half of autistic pupils feel that their teachers do not know how to support them and fewer than 50% of teachers feel confident in supporting autistic children (All Party Parliamentary Group on Autism, 2017) • Autistic pupils are twice as likely to be excluded from school than pupils who do not have SEND (Guldberg et al., 2022). • Young autistic people, particularly those from low-income families and from ethnic minority backgrounds, are less likely to begin post-secondary education or enter employment after secondary school (Crane, Adams, et al., 2019). Children and young people with ADHD face similar challenges in education:

	• One study of primary school-age children with ADHD found that this group is more likely to fall below expected attainment in school and have unauthorised absences; and report feeling less happy in school than their peers (May et al., 2021). • Untreated ADHD is associated with lower academic performance (Arnold et al., 2020). There is ongoing work in Cambridgeshire and Peterborough as part of Partnerships for Inclusion of Neurodiversity in Schools (PINS) to make schools more inclusive for every child (Pinpoint, 2023).
Employment and working conditions	Neurodivergent people report that many hiring processes are inaccessible to them, such as due to a lack of clarity in hiring processes (Davies et al., 2023). Autistic people face challenges and discrimination in the workforce: • The recent Buckland review found that only around 3 in 10 working-age autistic people are in employment, compared to 8 in 10 of non-disabled people; and that many autistic people face discrimination within work and feel that 'they must mask their autistic traits to succeed' (Buckland, 2024). • A range of research highlights that autistic people face poorer employment outcomes, including higher rates of unemployment, including among university graduates (DHSC, 2021a). Many autistic people who are employed work in precarious roles (such as short-term contacts or low-pay positions) and are more likely than to be underemployed or overqualified (Lindsay et al., 2021). • Young people who are not in work or education in the 3 years after leaving school are at a greater risk of poorer long-term outcomes, including poorer mental health. Young autistic adults may be more likely to not be in education or employment, as they can face particular challenges when entering adulthood (Eilenberg et al., 2019). A review of studies found some evidence that people with ADHD are more likely to be unemployed and to have experienced job instability, compared to the general population (Gordon and Fabiano, 2019).
Crime, safety and violence	The prevalence of ADHD and autism amongst people in prison may be substantially higher than in the general population, with estimates ranging from 20 to 50% (Criminal Justice Joint Inspection, 2022). Autistic people and people with ADHD are also more likely to experience bullying, violence and abuse. A meta-analysis found that people with ADHD are more likely to experience intimate partner violence and sexual violence than those who do not have ADHD (Arrondo et al., 2023). Autistic people are more likely to report experiences of bullying, child abuse and sexual violence than non-autistic people, with around half of autistic people having been bullied and 40% having experienced sexual abuse (Trundle et al., 2023).
Community wellbeing	Autistic people report much lower levels of life satisfaction than the general population, with one survey finding that autistic people are 8 times more likely to feel 'often' or 'always' lonely (NAS, 2021). Mental ill-health has a substantial impact on quality of life for autistic people (Oakley et al., 2021). There is evidence that both children and adults with ADHD have poorer quality of life than the general population, and that this relationship may partially explained by the increased rates of anxiety and depression in these groups (Yang et al., 2013).

Inequalities in mental health

- Some populations face inequalities in mental health: they are at a higher risk of experiencing poor mental health; of being underserved by mental health services and requiring targeted support to ensure that their needs are met.
- National research shows that some people autistic people and people with ADHD are more likely to experience poorer outcomes, including having contact with the criminal justice system, spending time in inpatient mental health settings, and experiencing homelessness. People with ADHD are also more likely to experience accidents and injuries (Brunkhorst-Kanaan et al., 2021).
- There are also inequalities in access to ADHD and autism assessments, and support services (Wallace-Watkin, Sigafoos and Waddington, 2023). For example:
    - Children whose first language is not English are less likely to have an autism diagnosis or autism-related support through an Education, Health and Care Plan (Roman-Urrestarazu et al., 2021b).
    - One study found that children whose mothers had educational qualifications at A-Level or higher were twice as likely to have a recorded autism diagnosis, compared to those whose mothers has lower levels of educational qualifications (Kelly et al., 2019).

	Evidence base
Deprivation	National data suggests that people living in more deprived areas are more likely to have been diagnosed with autism: in 2018, around 1 in 100 people living the most deprived quintiles in England had an autism diagnosis, compared to 1 in 170 of people in the least deprived areas (O'Nions et al., 2023). Similarly, national studies show that there are higher rates of ADHD diagnosis in more deprived areas (Hire et al., 2018).
Ethnicity	National research suggests children of 'white heritage' are 50% more likely to receive an autism diagnosis compared to children of 'Asian heritages' (Longfield, 2024). Another large national study found that, compared to White pupils, the autism diagnosis rates and access to support from EHCPs (Education, Health and Care Plans) were highest in Black pupils and lowest in Roma/Irish Traveller pupils (Roman-Urrestarazu et al., 2021b). Some research indicates that families from Black, Asian and minority ethnic groups with autistic children can face barriers when trying to access an autism diagnosis and when getting support from services and within their local community. Families suggest that this can happen due to a range of reasons, including a lack of knowledge around autism, historic negative experiences of healthcare services and a lack of cultural competency within health and education services (Slade, 2014). Some UK research suggests that there is no difference in the prevalence of ADHD symptoms among adults (NHS Digital, 2014). However, international research suggests that children from minoritised ethnic groups are less likely to be diagnosed with ADHD and prescribed ADHD medication than their peers (Slobodin and Masalha, 2020). Some studies also suggest that children from minoritised ethnic groups can face prejudice in the perception of behaviour and ability (Slobodin and Masalha, 2020).
Gender	Around 1 in 80 boys and men in the UK had been diagnosed with autism in 2018, compared to 1 in 280 girls and women (O'Nions et al., 2023). Boys are more likely to be diagnosed with autism and are almost 5 times as likely to have an EHCP, compared to girls (Roman-Urrestarazu et al., 2021b). Autistic women and girls may be more likely to have their autism 'missed', for a range of reasons (Lockwood Estrin et al., 2021). There is also some research suggesting that there

	are higher rates of undiagnosed autism amongst transgender and gender-diverse people (Ward, 2019). NICE guidelines highlight that ADHD is more commonly diagnosed in boys than girls, but that differences in presentation (boys present more often with disruptive behaviour and are more likely to have conduct disorder; whilst girls are more likely to have the inattentive subtype of ADHD) may contribute to these differences (NICE, 2023).
LGBTQ+	Autism and ADHD are more common amongst trans and gender diverse individuals, both 'marginalized groups where the currently available support and understanding is inadequate' (Warrier et al., 2020).
Care experienced	Around 3% of 'looked after' children in England are recorded as having autism, however this is likely to be an underestimate of true figures (Parsons et al., 2019). Some studies suggest that ADHD is more common among 'looked after' children than the general population, but that these findings should be interpreted cautiously (Heady et al., 2022).
Disability/long-term physical health conditions	The strong bidirectional relationship between physical and mental health is likely to contribute to higher rates of mental ill-health amongst autistic people and people with ADHD, although there is limited research looking into co-morbidity in these populations. • Reviews show that some physical health conditions are more common in autistic people than the general population, including sleep problems, epilepsy, and autoimmune conditions (Rydzewska, Dunn and Cooper, 2021), and that autistic people can face a range of barriers to accessing physical healthcare (Mason et al., 2019; Walsh et al., 2020). • There is less research into the physical health needs of people with ADHD, although a recent review identified an increased risk of obesity, asthma and sleep disorders associated with ADHD (Instanes et al., 2018). Chronic pain may be more common among people with ADHD (Battison et al., 2023).
Severe multiple disadvantage	Severe multiple disadvantage (SMD) is a term used to describe people experiencing a combination of mental ill health, homelessness, substance use, domestic abuse, and/or offending (Harland et al., 2022). Some groups argue that neurodivergence should be considered as an aspect of SMD, as people can be disadvantaged because of a lack of support around neurodivergence. Examples include (Revolving Doors, 2022): • Substance use to 'mask' neurodivergent behaviours. • The behaviour of neurodivergent people is often misinterpreted, potentially making them more likely to be arrested. • Neurodiverse conditions often go unrecognised and/or are not always considered as part of mitigating circumstances within the criminal justice system.

Additional Resources

- NHS England guidance: Supporting people with a learning disability and autistic people to live happier, healthier, longer lives: Bitesize guide for local systems
- Diverse perspectives: the challenges for families affected by autism from Black, Asian and Minority Ethnic communities
- Housing for people with a learning disability or autistic people
- Supporting autistic flourishing at home and beyond: Considering and meeting the sensory needs of autistic people in housing
- Autism and Homelessness Toolkit
- Autism and school exclusion and autism acceptance in schools resources
- Neurodiversity in the criminal justice system: A review of evidence

Assessment, diagnosis and management

- There are increasing numbers of children and adults referred for ADHD and autism assessments in Cambridgeshire and Peterborough, which has not been matched by an increase in service capacity.
- A range of factors may have contributed to this increase in demand, including changes in diagnostic criteria for autism and ADHD, greater awareness of these conditions and how they present in girls and women, and greater awareness of ADHD treatment.
- Waiting times to access ADHD and autism assessments has been repeatedly raised as an important issue by people in Cambridgeshire and Peterborough (Sidney, 2023, 2024).

Right to Choose and private healthcare

- People living in England have had a legal right to choose their mental healthcare provider (the 'Right to Choose') through the NHS since 2018 (NHS, 2023). This mean that they can choose any organisation that holds a single contract with the NHS, regardless of geographic location. People can also self-fund private healthcare assessments.
- These services may provide autism/ADHD assessments only; ADHD assessments and medication titration; or ADHD assessment, medication titration, and ongoing shared care.
- The SUN Network reports that people who are referred through 'Right to Choose' are often not aware that they are not automatically eligible for ADHD medication or post-diagnostic support from NHS following the diagnosis (Sidney, 2023).
- There can also be issues around the provision of Shared Care:
    - NICE guidelines states that after ADHD medication has been optimised, prescriptions and annual reviews should be carried out under a 'Shared Care Protocol' within primary care (Cambridgeshire and Peterborough ICS, 2013).
    - Some people may be diagnosed through private or Right To Choose services that do not include ongoing shared care, hence people may need to access medications privately.
    - Specialist ADHD services are asked to provide guidance and advice to GPs around ADHD medication, on a yearly basis. Due to the rising numbers of people receiving ADHD medication, this has led to increasing demands these services.
- There is ongoing work to looking into how to address these issues within the ICS, including additional support for GPs around Shared Care Protocols.

ADHD

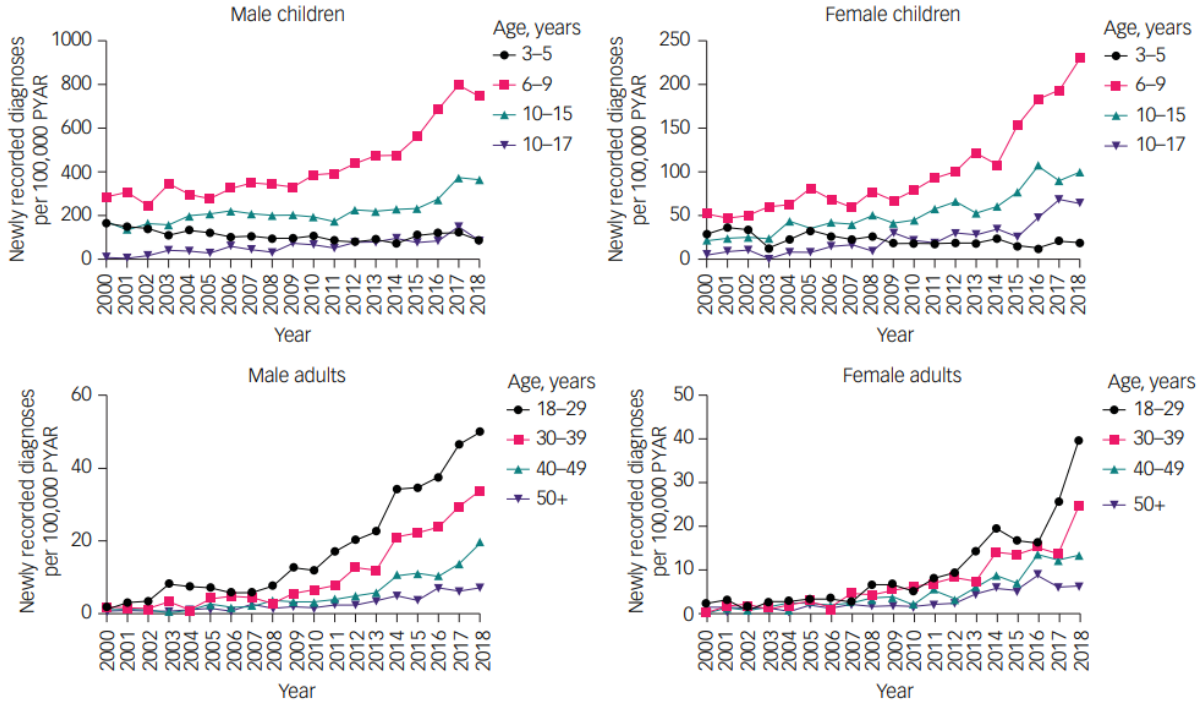
Both people with ADHD and healthcare professionals have raised multiple challenges relating to ADHD diagnostic pathways and treatment, including recent issues in the supply of ADHD medication (Russell, Hinwood and Fuller, 2024).

- In England, the increased demand for ADHD assessments in recent years has not been matched by increased workforce and funding for assessment services. This has led to 'unprecedented' waiting times to access ADHD assessments and treatments, for which there are currently no national targets to address (M. Smith, 2023; Smith et al., 2023).
- More recent understanding of ADHD as a lifelong condition, rather than something that only occurs in childhood, has led to greater recognition of the needs of adults with ADHD (Adamou, no date).
- Some groups of people with ADHD are more likely to face inequalities in terms of access, experience and outcomes of ADHD services, including people in contact with the criminal justice system and people living in more deprived areas (Russell, Hinwood and Fuller, 2024).

Increasing numbers seeking assessments

As shown in the graph below, increasing numbers of people have been assessed for and diagnosed with ADHD over the past 20 years. Between 2000 and 2018, there was a 20-times increase in the ADHD diagnoses in men aged 18 – 29 in the UK (McKechnie et al., 2023). A range of factors may have contributed to this increase, including greater awareness of ADHD and treatments, and changing attitudes around ADHD (McKechnie et al., 2023). There are also some reports that the wider impacts of the COVID-19 pandemic, such as lockdown requirements, heightened core ADHD traits in some people (Hollingdale, Adamo and Tierney, 2021).

Figure 11: Time trends of new ADHD diagnoses in children and adults in the UK, by age group and gender. Note the different y-axes. Image source: McKechnie, et al. 2023



This study also found that whilst the male-to-female ratio of ADHD diagnoses was around 4:1 in childhood, there were similar rates of diagnosis in adults over 50. This may reflect that women are more likely to be diagnosed with ADHD later in life, potentially because ADHD can be under-recognised in girls (McKechnie et al., 2023). Some people with ADHD report that perimenopause and the menopause is a period when ADHD has the greatest impact on their day-to-day life (Wasserstein, Stefanatos and Solanto, 2023). However, there is a lack of research into this relationship (Camara, Padoin and Bolea, 2022).

Impact of diagnosis on mental health

- A systematic review shows that receiving a diagnosis of ADHD can allow people to better understand their needs, and access support and interventions (French et al., 2023). Medication used to manage ADHD traits has been shown to substantially improve outcomes.
- French et al.'s 2023 review showed that undiagnosed ADHD can have substantial impacts of people's day-to-day life and was associated with lower quality of life and social difficulties; higher rates of depression, anxiety and substance use; poorer outcomes in education and employment; poorer physical health and higher rates of offending (French et al., 2023).
- Some research suggests that the early management of ADHD symptoms may reduce the risk of people developing depression and bipolar disorder, as well as being associated with a 50% decrease in the risk developing 'substance use disorders' (Katzman et al., 2017).
- Some research suggests that the use of medication to manage ADHD traits is associated with a reduction in offending (Lichtenstein et al., 2012).

Diagnosis

Children and young people

- International research highlights that boys, younger children, white children, and children from urban areas and higher socioeconomic backgrounds are more likely to access ADHD care (assessment and interventions) in childhood (Wright et al., 2015).
- Studies show that parents can face a range of barriers to accessing ADHD services for their children (Kappi and Martel, 2022), although one of the most reported barriers is a lack of information about who can help (Sayal et al., 2015).

The pathways for ADHD assessments in Cambridgeshire and Peterborough are set out below:

	0-5 years	5-11 years	11-18 years
Cambridgeshire	Community paediatrics (CCS)	Community Paediatrics (CCS)	YOUnited
Peterborough	Community paediatrics (CPFT)	YOUnited	YOUnited

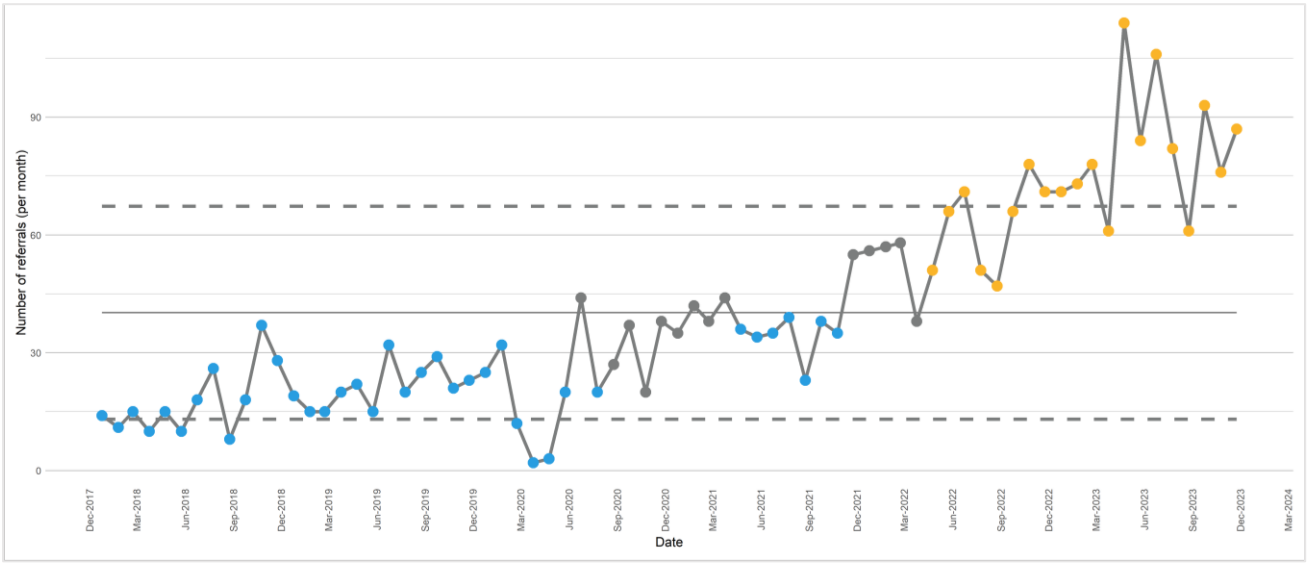
In Peterborough, the community paediatrics service is the Peterborough Integrated Neurodevelopmental Service. This service provides an integrated model, in which children can be assessed for ADHD, autism and learning disabilities. The introduction of this service has significantly reduced waiting times and increased the capacity to deliver mental health assessments and post-diagnostic support (Embracing Complexity, 2019).

Parents in Cambridgeshire are required to have previously engaged with an evidence-based parenting course before their child is referred for an ADHD assessment. However, from 1st April 2024, parents in Peterborough will no longer need to undertake a parenting programme before referral to the neurodevelopmental pathway.

Referral rates

Referrals to children and young people's ADHD services in Cambridgeshire and Peterborough have shown a significant increase from May 2022 – 2024. This has resulted in an substantial waiting list to access this service.

Figure 12: Total referrals to children and young people's ADHD services, Central ADHD CAMHS, North ADHD CAMHS and South ADHD CAMHS, January 2018 – December 2023. Data source: CPFT

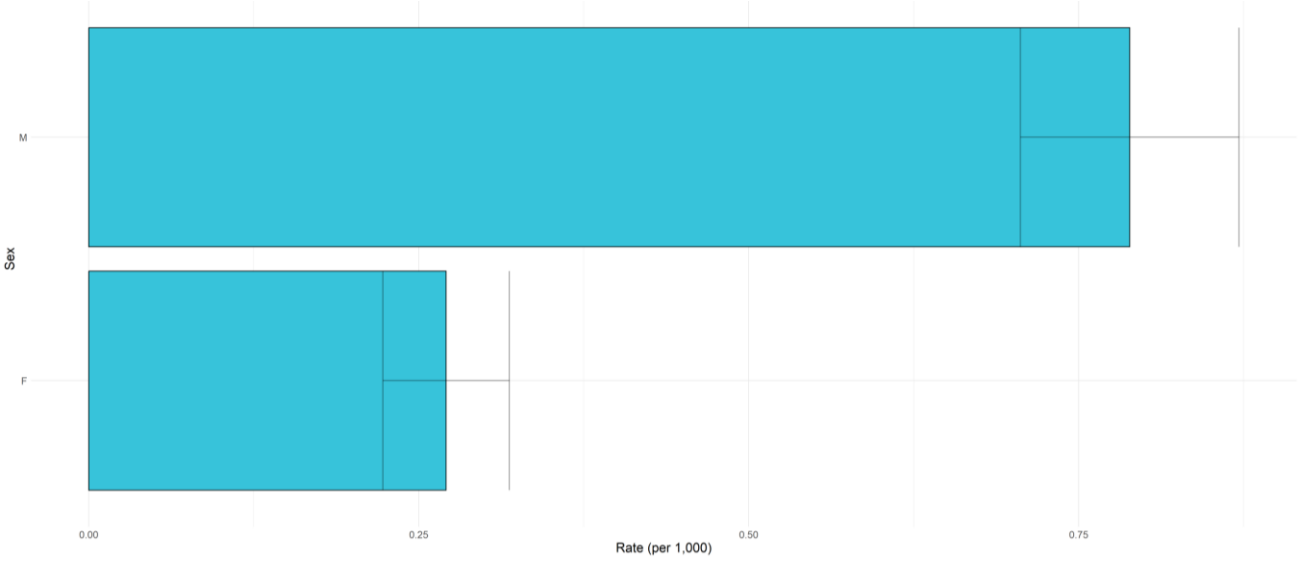


Note: this is only a partial picture, as these figures are only for children aged 11+ for ADHD services in Central and South Cambridgeshire CAMHS. They include under 11s for North CAMHS, but not referrals to community paediatrics (in CPFT or CCS) for pre-school and primary school children.

Referrals by demographic group

Between January 2018 and December 2023, boys were significantly more likely to be referred to children and young people's ADHD services in Cambridgeshire and Peterborough than girls.

Figure 13: Referral rate per 1,000 by sex, Central ADHD CAMHS, North ADHD CAMHS and South ADHD CAMHS, January 2018 – December 2023. Data source: CPFT

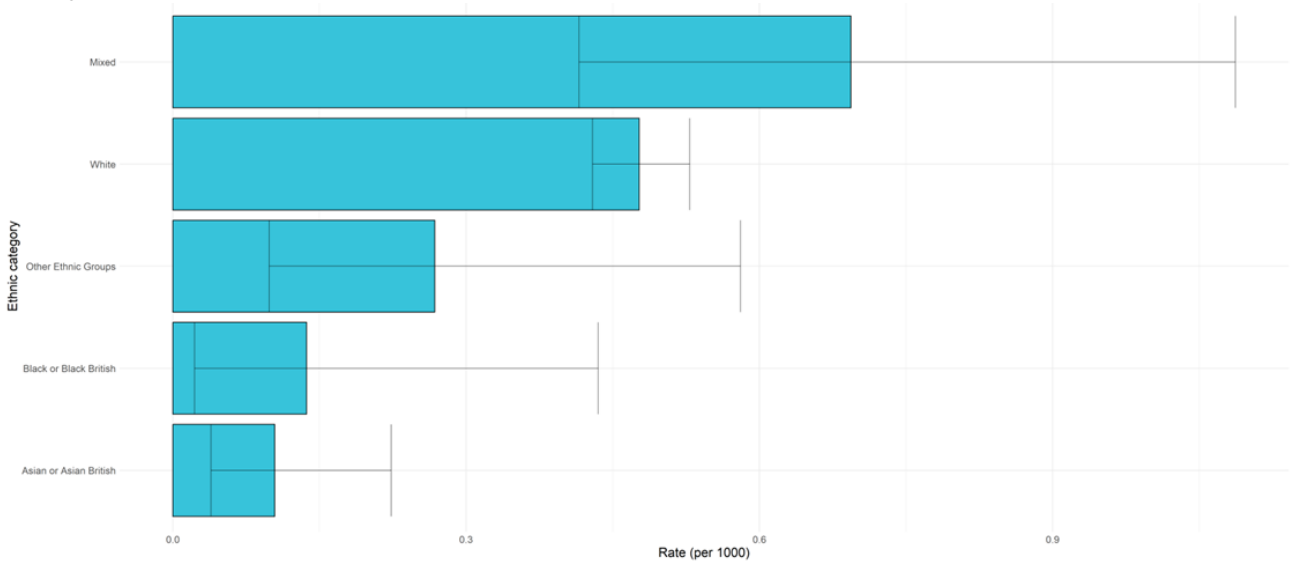


Note: this is only a partial picture, as these figures are only for children aged 11+ for ADHD services in Central and South Cambridgeshire CAMHS. They include under 11s for North CAMHS, but not referrals to community paediatrics (in CPFT or CCS) for pre-school and primary school children.

Between January 2018 and December 2023, the highest rate of referrals were seen from 'Mixed' and 'White' ethnic groups. A substantially lower rate of referrals was seen from 'Black or Black British' and 'Asian or Asian

British' ethnic groups. The teams in children and young people's ADHD services are currently implementing the Patient Carer Race Equality Framework (PCREF) to try and understand this better.

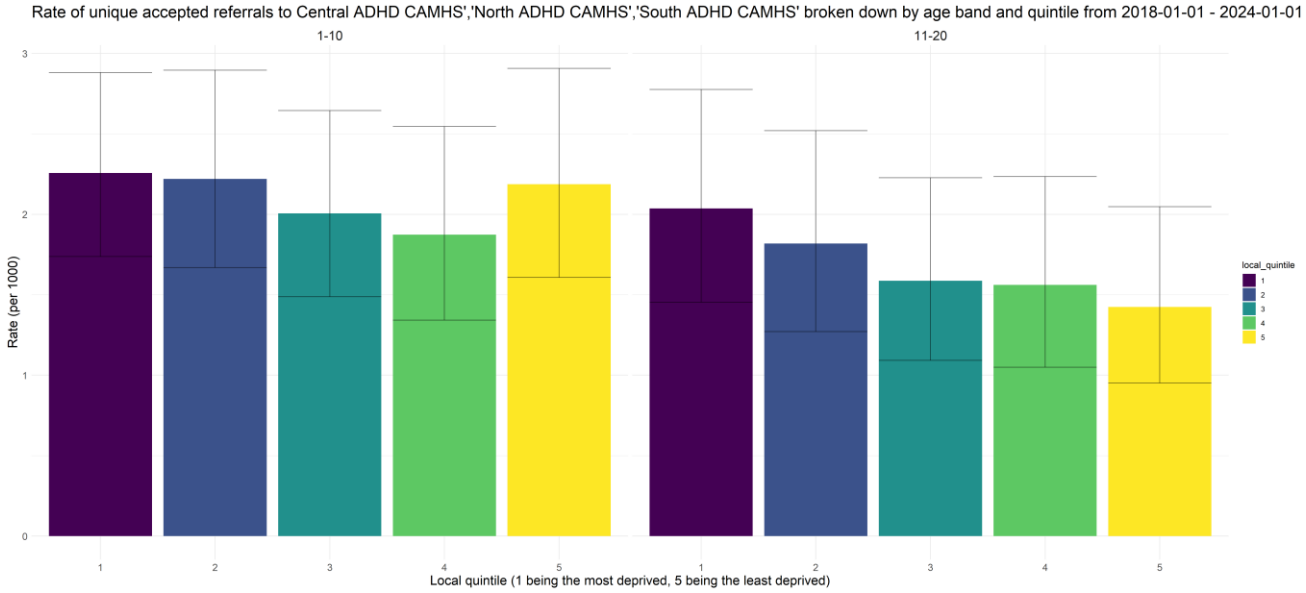
Figure 14: Referral rate per 1,000 by sex, Central ADHD CAMHS, North ADHD CAMHS and South ADHD CAMHS, January 2018 – December 2023. Data source: CPFT



Note: this is only a partial picture, as these figures are only for children aged 11+ for ADHD services in Central and South Cambridgeshire CAMHS. They include under 11s for North CAMHS, but not referrals to community paediatrics (in CPFT or CCS) for pre-school and primary school children.

Between January 2018 and December 2023, there no significant differences in the rate of referrals into children and young people's ADHD services by deprivation in Cambridgeshire and Peterborough, either for children aged 1-10 and 11-20.

Figure 15: Referral rate per 1,000 by deprivation quintile, Central ADHD CAMHS, North ADHD CAMHS and South ADHD CAMHS, January 2018 – December 2023. Data source: CPFT



Note: 1 indicates the quintile with the highest, and 5 the lowest, level of deprivation. This analysis only gives a partial picture as it is based on referrals of children and young people aged between 11 and 20.

Adults

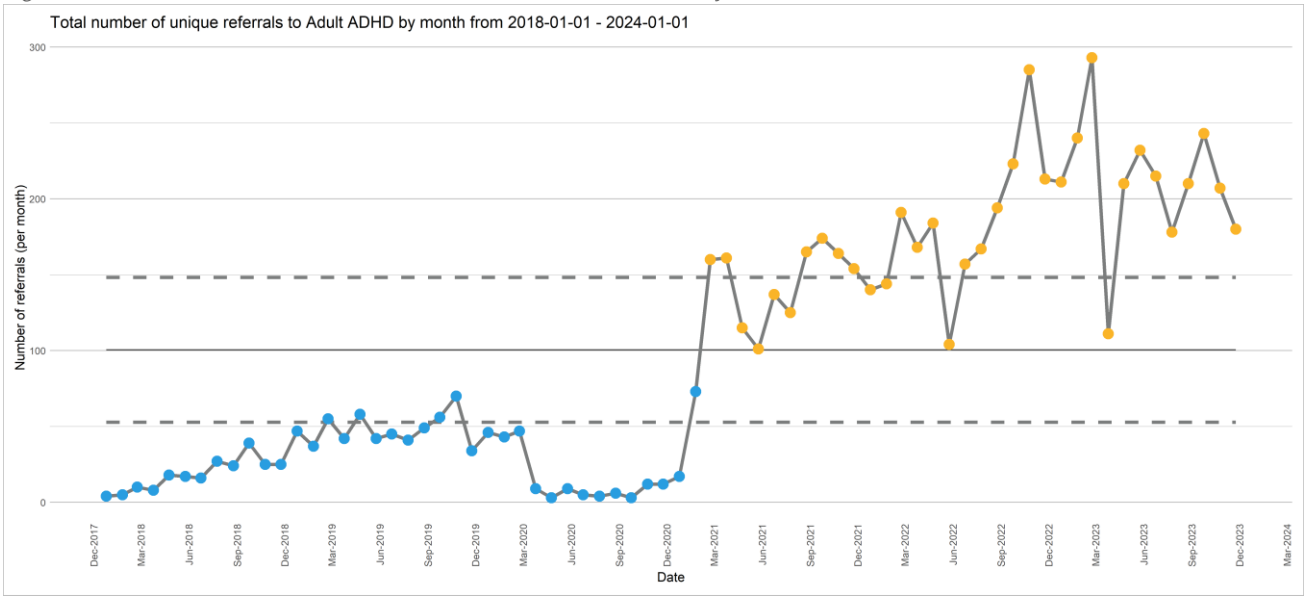
The Cambridgeshire and Peterborough Adult ADHD clinic is a specialist service offering assessment, diagnosis and treatment for adults with possible ADHD and for those with previously diagnosed ADHD. The clinic also offers pre-referral advice for GPs, including around medication monitoring and symptoms management.

- Referrals into this service are from GPs, who can refer people to the Primary Care Mental Health Service (PCMHS) where people receive an initial triage. There has been a substantial increase in the number of adults referred to the ADHD clinic since 2019/20. Referrals to the Adult ADHD clinic were closed between March 2020 and February 2021.
- Currently there is no joined up pathway between adult ADHD and autism assessment services in Cambridgeshire and Peterborough. If someone is identified as potentially having autism during their ADHD assessment, they can only access an assessment by joining the waiting list for CLASS.

Referral rates

Referrals to the Adult ADHD service in Cambridgeshire and Peterborough have shown a significant increase from May 2022 – 2024. This has resulted in an substantial waiting list to access this service.

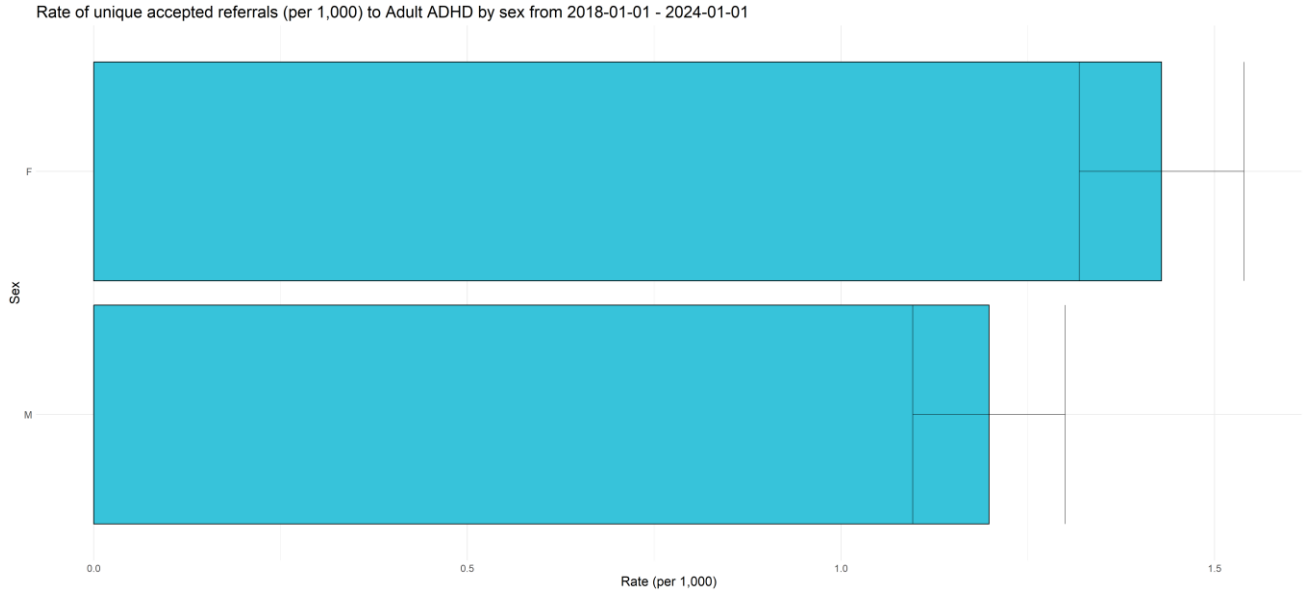
Figure 16: Total referrals to the CPFT Adult ADHD service, January 2018 – December 2023. Data source: CPFT



Referrals by demographic group

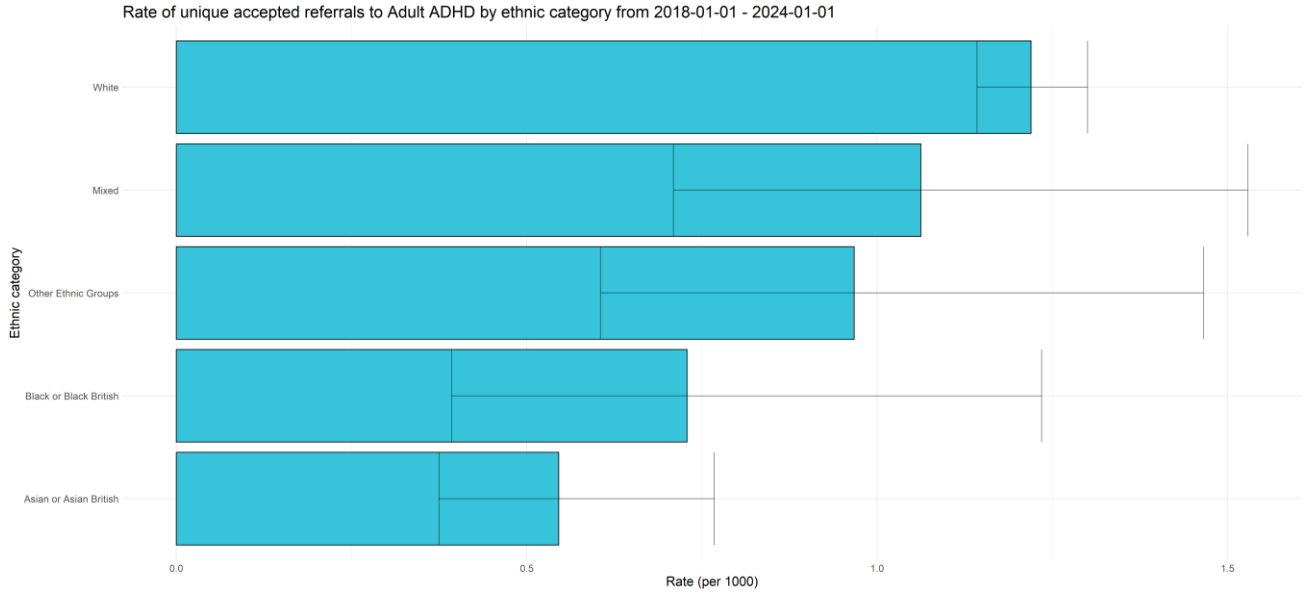
Between January 2018 and December 2023, women were significantly more likely to be referred to the Adult ADHD service. This may reflect that women are less likely to be diagnosed with ADHD as children (McKechnie et al., 2023).

Figure 17: Referral rate per 1,000 by sex, Adult ADHD service, January 2018 – December 2023. Data source: CPFT



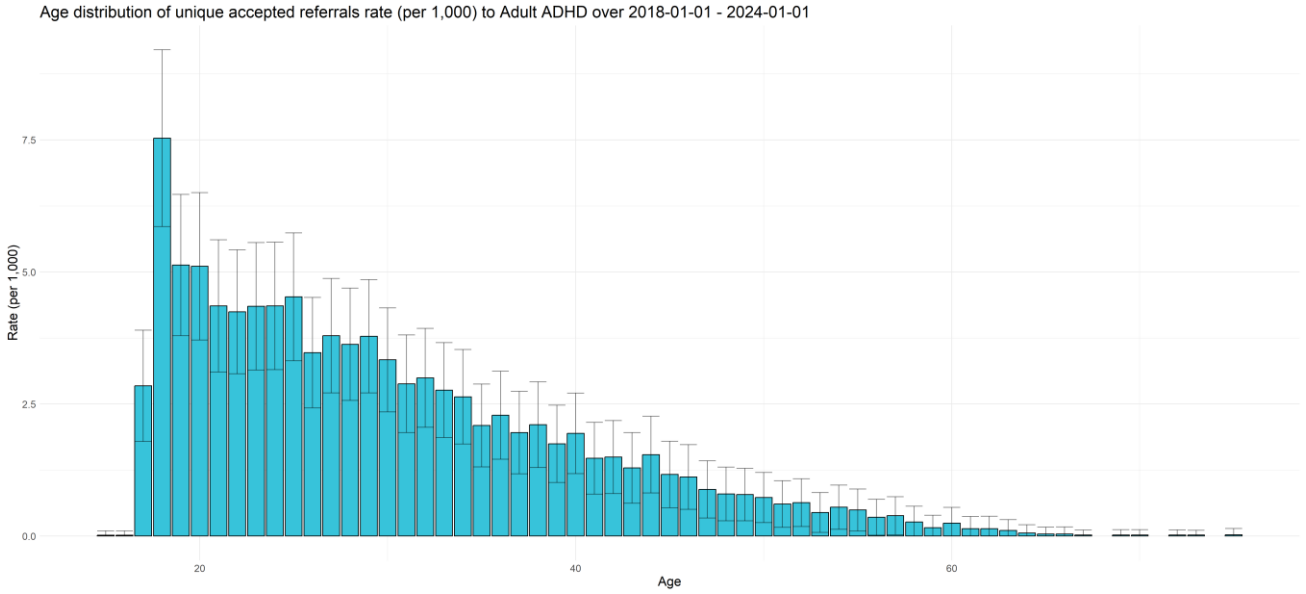
Between January 2018 and December 2023, the highest rate of referrals were seen from 'White' and 'Mixed' ethnic groups. A substantially lower rate of referrals was seen from 'Asian or Asian British' ethnic groups.

Figure 18: Referral rate per 1,000 by ethnic group, Adult ADHD service, January 2018 – December 2023. Data source: CPFT



Between January 2018 and December 2023, the highest rate of referrals to the Adult ADHD service were for young adults between 18 and 25.

Figure 19: Referral rate per 1,000 by age, Adult ADHD service, January 2018 – December 2023. Data source: CPFT



Management

- NICE guidelines state that people with ADHD should have a 'comprehensive, holistic shared treatment plan that addresses psychological, behavioural and occupational or educational needs' (NICE, 2018). This may include considering changes to the environment such as adjustments in school or work, medication and non-pharmacological interventions.
- NICE guidelines state that children (aged 5+), young people and adults should be offered ADHD medication if their ADHD symptoms still cause 'persistent significant impairment' in at least one area of their life, after environmental modifications have been implemented and reviewed. They also state that people receiving pharmacological treatment for ADHD should have regular reviews in primary care to monitor effectiveness and adverse impacts (NICE, 2018).
- There has been a substantial increase in the number of people prescribed ADHD medications, with a 50-times increase in ADHD prescriptions in men aged 18-29 in the UK from 2000 to 2018 (McKechnie et al., 2023). However, research suggests that if everyone with severe symptoms of ADHD received medication, this would be at least 1% of the population, suggesting a significant unmet need (Asherson et al., 2022).
- National data shows that rates of ADHD prescriptions are higher in men, children and people from more deprived areas (McKechnie et al., 2023).

Children and young people

- Support for children and young people with ADHD should be provided alongside support in education and children's services, such as reasonable adjustments in school (NICE, 2018).
- Young adulthood is often associated with a decrease in ADHD medication use (Asherson et al., 2022). This has been linked to difficulties in the transition to adult services, rather than changes in ADHD symptoms, with some suggesting this shows unmet needs in this age group (Asherson et al., 2022).
- There is limited high-quality research assessing the impact of psychological therapy in managing ADHD symptoms in children and young people (Ford, 2020). Some early evidence suggests there may be benefits from acceptance and commitment therapy (ACT) (Munawar et al., 2021).

Adults

The use of medication to manage ADHD symptoms has a strong evidence base, with reviews showing that these treatments reduce ADHD traits in adults (De Crescenzo et al., 2017) and are associated with reduced rates of depression, substance use, criminality and suicidality (Boland et al., 2020). There are currently shortages of ADHD

medication across the UK, which has had a significant impact on the day-to-day lives of many people with ADHD (Gordon, 2024).

There is less high-quality research evaluating the impact of non-pharmacological interventions on adults with ADHD. However, some studies suggest that some adults with ADHD can benefit from cognitive behavioural therapy (CBT), mindfulness and dialectical behaviour therapy (DBT) (De Crescenzo et al., 2017).

The CPFT Adult ADHD service is not currently commissioned to deliver psychoeducation.

Additional Resources

- The Adult ADHD Assessment Quality Assurance Standard (AQAS)
- Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology
- QbTest for the assessment of attention deficit hyperactivity disorder (ADHD)

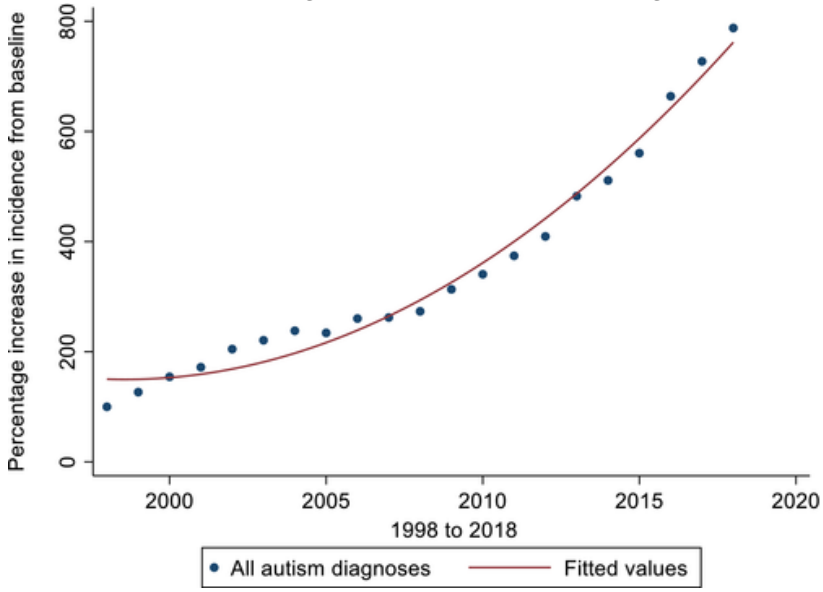
Autism

- There is increasing demand for autism assessments across England, which has not been matched by an increase in capacity. As a result, many people wait 'much longer than the 3-month recommended in NICE guidelines for an autism assessment to begin and the 18-week maximum waiting time for treatment to begin' (NHS England, 2023a).
- Likewise, there is a 'substantial mismatch in supply and demand of number of [autism] diagnostic assessments commissioned' in Cambridgeshire and Peterborough (Public Health Team CCC & PCC, 2020).
- The NHS introduced a new framework for diagnostic assessment pathways for autism in 2024 (NHS England, 2024a). This framework aims to address long waiting times, improve the quality of information and support provided during and after assessment, and to improve the ease and efficiency of progression through the autism pathway.

Increasing numbers seeking assessments

There was a 787% increase in incidence of autism diagnoses in the UK from 1998 to 2018, which a particular increase in diagnoses in adults, and women and girls (Russell et al., 2022). Changes in the diagnostic criteria for autism and a growing awareness of the different ways autism can present (particularly in women and girls) may have contributed to this increase (Brede et al., 2022).

Figure 20: Percentage increase in new autism diagnoses, UK, 1998 – 2018. Image source: Russell et al. 2021



Note: this graph uses the number of new diagnoses in 1998 as the baseline (100%)

It is estimated that 0.82% of people in England have a formal autism diagnosis. A further 0.77% – 2.22% (between 435,700 and 1,197,300 people) may also be autistic but had not received a diagnosis as of 2018 (O'Nions et al., 2023). Many people with undiagnosed autism are adults, a high proportion of whom are aged 50+.

Impact on diagnosis on mental health

NHS guidelines on autism assessments set out four key reasons why 'universal, equitable and timely access' to autism assessments are important (NHS England, 2023a):

1) Healthcare: diagnosis can allow people to access specialist support services (e.g. safe and effective interventions to improve communication or wellbeing).
2) Reasonable adjustments: diagnosis can inform clinical decisions about which interventions are best for individuals (NHS England, 2023d). For example, some mental health interventions are less effective for autistic people (Li et al., 2022).
3) Validation and self-identity: receiving an autism diagnosis as an adult can mean different things to different people. It can be an empowering experience that can help autistic adults to accept themselves and understand difficulties they have faced throughout their lives (Lai and Baron-Cohen, 2015). People who receive external support and autism acceptance are more likely to develop a positive 'autistic identity', which is associated with higher wellbeing and lower rates of internalised self-stigma, psychological distress and depression (Davies et al., 2024).
4) Wider determinants of health: access to an autism diagnosis may allow opportunities to better meet mental health needs and reduce risk factors for poor mental health, such as adjustments in employment.

Undiagnosed autism is associated with poorer mental health, including 2.7 times greater likelihood of lifetime mental illness (Jadav and Bal, 2022; French et al., 2023). Autistic people who do not have a clinical diagnosis may be unable to access appropriate mental healthcare, improved personal understanding, workplace adjustments and protection from discrimination (NHS England, 2023a). Hence, timely access can potentially reduce the escalation of poor mental health and the need for inpatient mental health admissions (NHS England, 2023c).

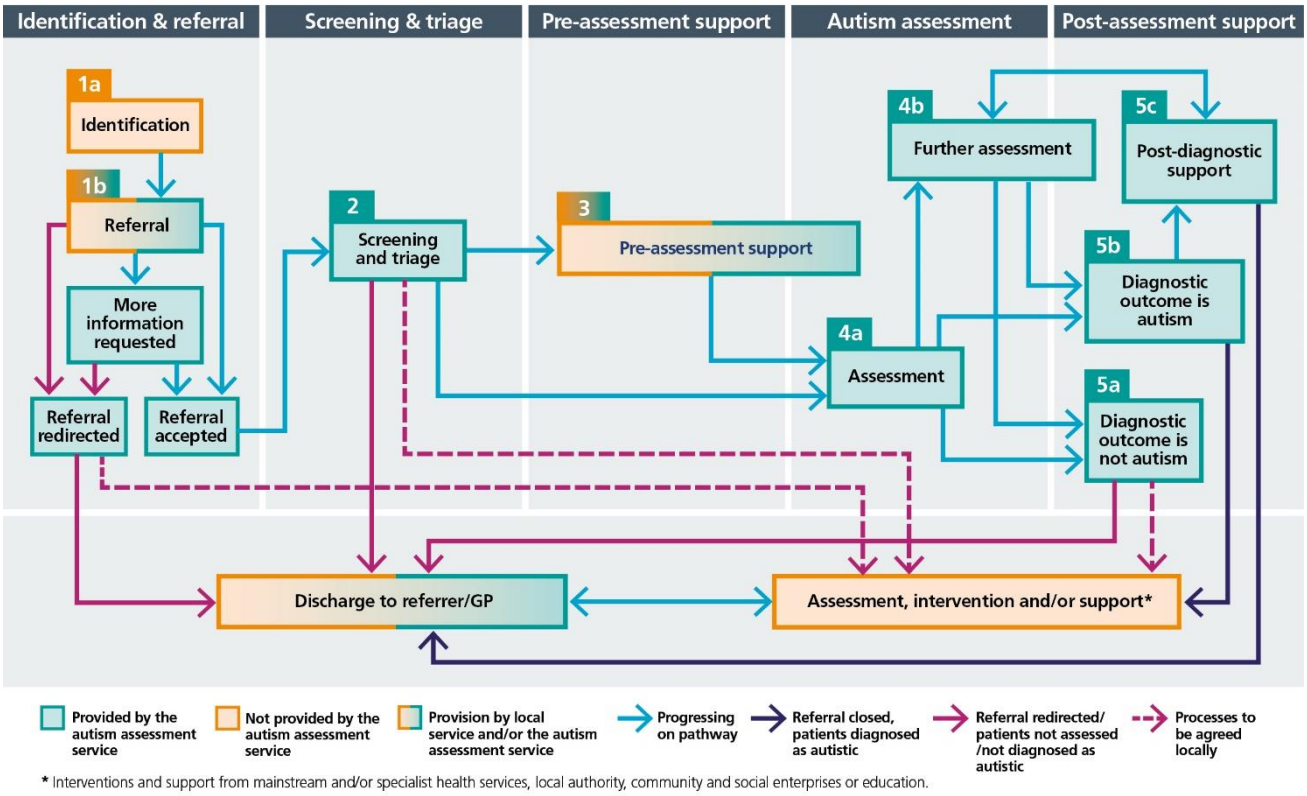
A recent report highlights that failing to provide autistic children with the support can have a long-term impact on their outcomes, including physical and mental health outcomes, and greater risk of school exclusion (Longfield, 2024).

Autism assessment pathway

National guidance outlines 5 stages in autism assessment pathways:

1) Identification of possible autistic traits and referral to relevant service
2) Screening and triage
3) Pre-assessment support
4) Autism assessment
5) Post-assessment support

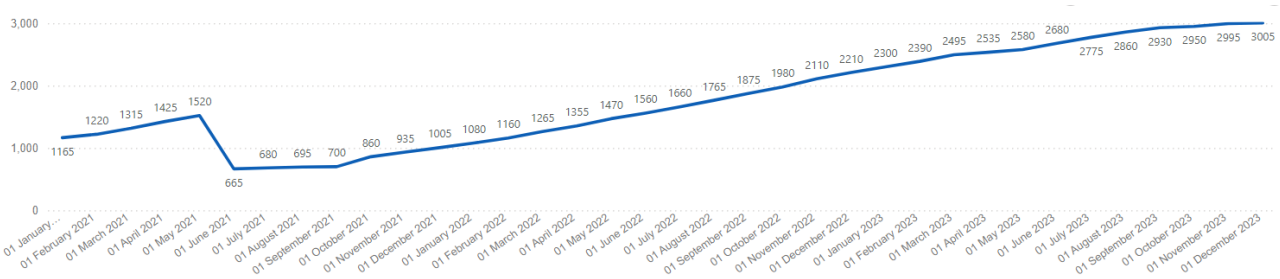
Figure 21: Generic autism assessment pathway. Image source: [Operational guidance to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards]



Waiting list overview

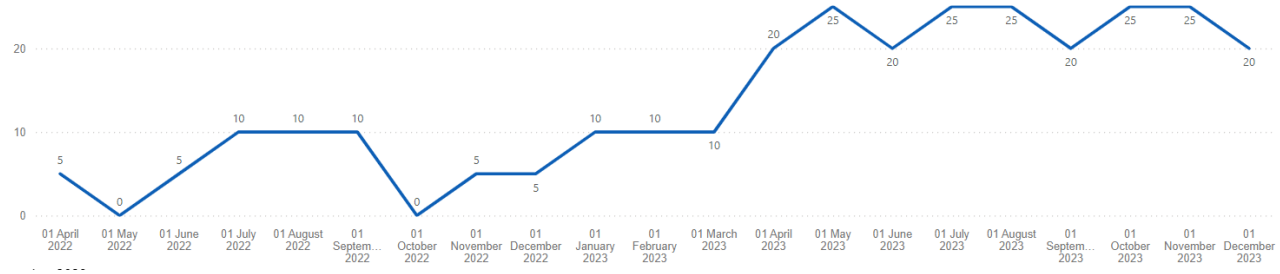
In the UK, people have been waiting for longer for autism assessments since the COVID-19 pandemic (DHSC, 2021a). The same is true in Cambridgeshire and Peterborough, where there has been a substantial increase in the number of people with an open referral to autism services (waiting for an autism assessment) in Cambridgeshire and Peterborough from mid-2021 to 2023. These numbers may underestimate the true level of need, as people may not know how to access services or perceive that waiting lists are too long to seek out an assessment.

Figure 22: Number of patients with an open 'suspected autism' referral in the month, Cambridgeshire and Peterborough ICB, all ages, January 2021 – December 2023. Image source: [Autism Statistics, April 2022 to March 2023 - NHS England Digital]



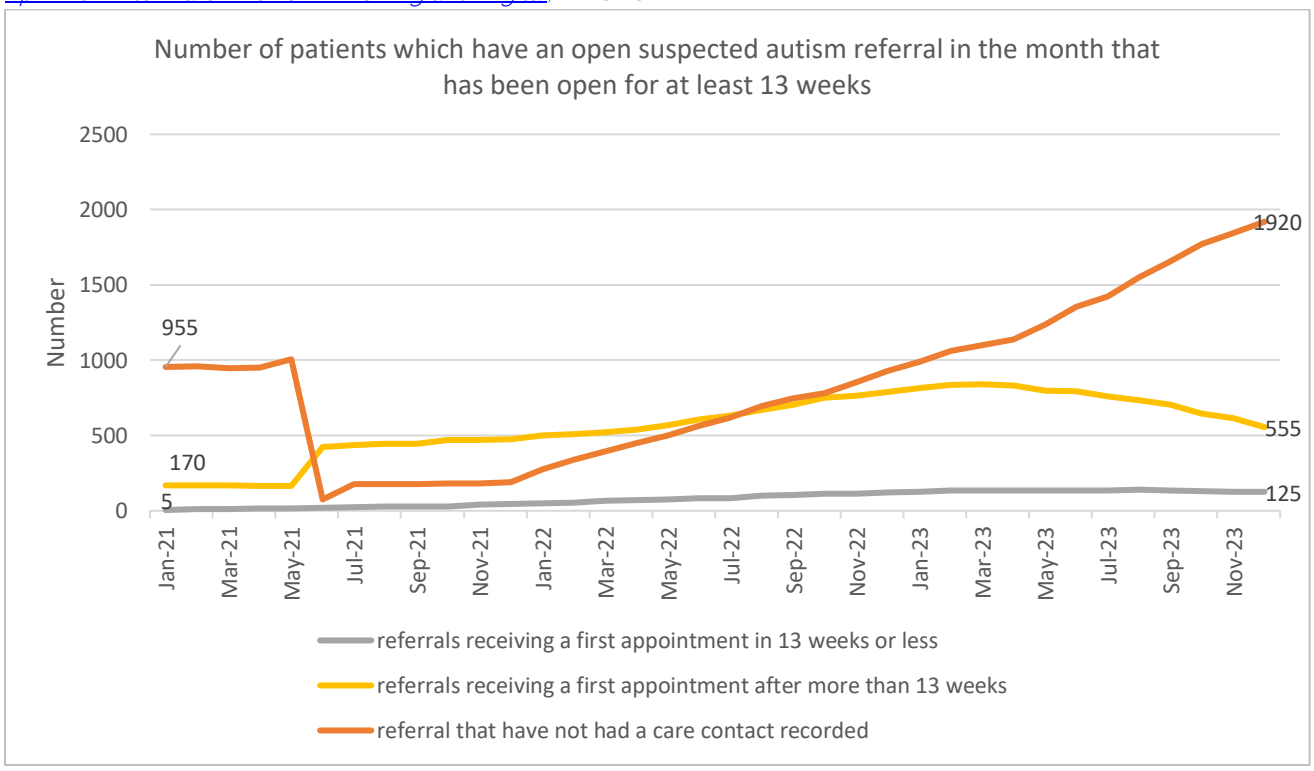
The total number of open referrals for 'suspected autism' received each month has increased to 20 - 25 in recent months, compared to 10 or less in 2022.

Figure 23: Number of patients with an open 'suspected autism' referral receiving an autism diagnosis in the month, Cambridgeshire and Peterborough ICB, all ages, January 2021 – December 2023. Image source: Autism Statistics, April 2022 to March 2023 - NHS England Digital



In line with national trends, people are waiting longer for appointments at autism assessment services in Cambridgeshire and Peterborough. The number of referrals for 'suspected autism' that have been open for at least 13 weeks and have not had a care contact has increased sharply since June 2021. By December 2023, there was over 1,900 people waiting for more than 13 weeks who had not had any care contact, 74% of all referrals.

Figure 24: Number of patients which have an open 'suspected autism' referral in the month that has been open for at least 13 weeks, Cambridgeshire and Peterborough ICB, January 2021 – December 2023. Data source: Autism Statistics, April 2022 to March 2023 - NHS England Digital, MHSDS



Diagnosis

Children and young people

A review of UK parents' experiences of their child receiving an autism diagnosis found (Legg and Tickle, 2019):

- Some reported that GPs did not recognise or dismissed parents when they suggested their child might be autistic.
- Some parents were able to receive timely assessments for their child, whilst others felt that long waits to accessing a diagnosis had a negative emotional impact on their family.
- Parents reported a range of emotions post-diagnosis, from shock to relief.

The pathways for autism assessments in Cambridgeshire and Peterborough are set out below:

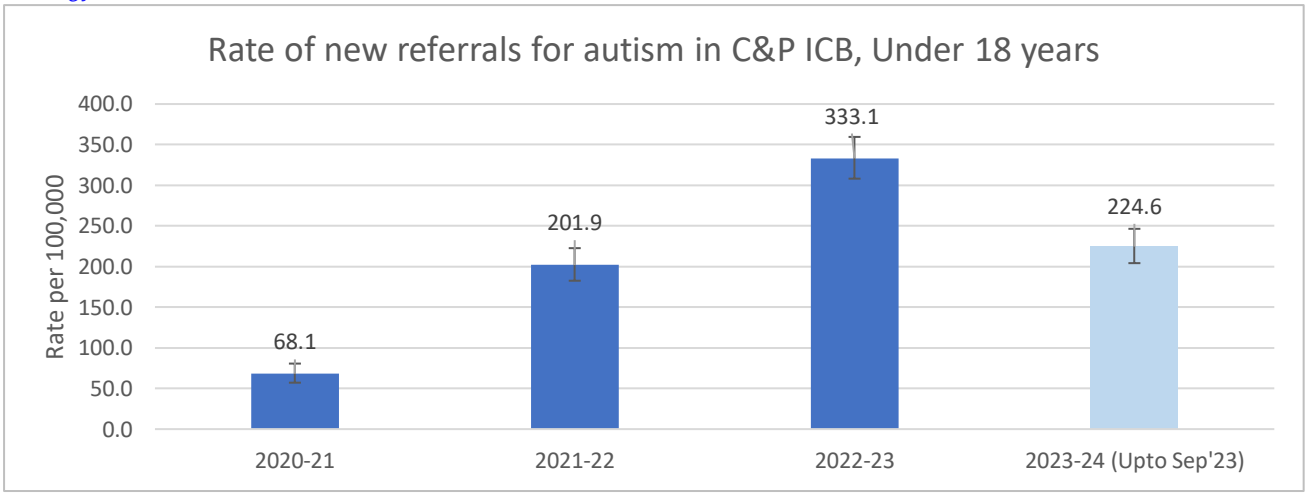
	0-5 years	5-11 years	11-18 years
Cambridgeshire	Community paediatrics (CCS)	Community Paediatrics (CCS)	YOUnited
Peterborough	Community paediatrics (CPFT)	YOUnited	YOUnited

In Peterborough, the community paediatrics service is the Peterborough Integrated Neurodevelopmental Service. This service provides an integrated model, in which children can be assessed for ADHD, autism and learning disabilities. The introduction of this service has significantly reduced waiting times and increased the capacity to deliver mental health assessments and post-diagnostic support (Embracing Complexity, 2019).

Referral rates

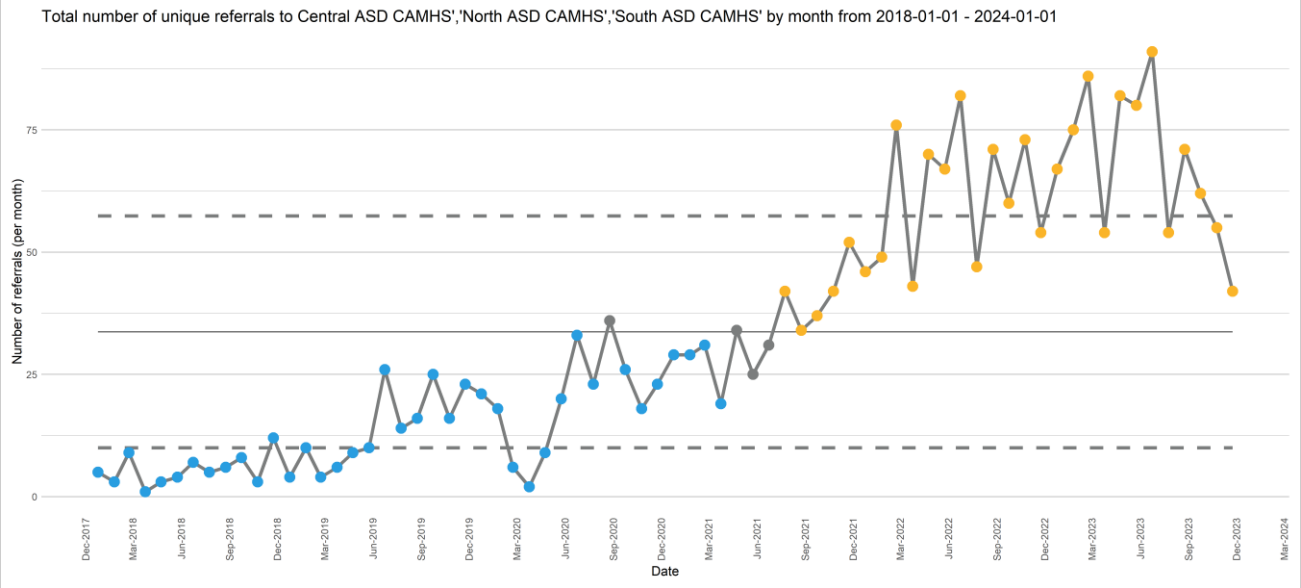
In Cambridgeshire and Peterborough, the number of children referred for an autism assessment has increased from 2020/21 to 2022/23.

Figure 25: Rate of new referrals for autism assessments per 100k population, under 18s, Cambridgeshire and Peterborough ICB, 2020/21 – 2023/24 (up to September 2023). Data source: Autism Diagnostic Dashboard - Autism Strategy Dashboards - FutureNHS Collaboration Platform



When examined on a month-by-month basis, data shows that referrals to children and young people's autism assessment services in Cambridgeshire and Peterborough have shown a significant increase from August 2021 to December 2023.

Figure 26: Referrals to children and young people's autism assessment services, Central ASD CAMHS, North ASD CAMHS and South ASD CAMHS, January 2018 – December 2023. Data source: CPFT

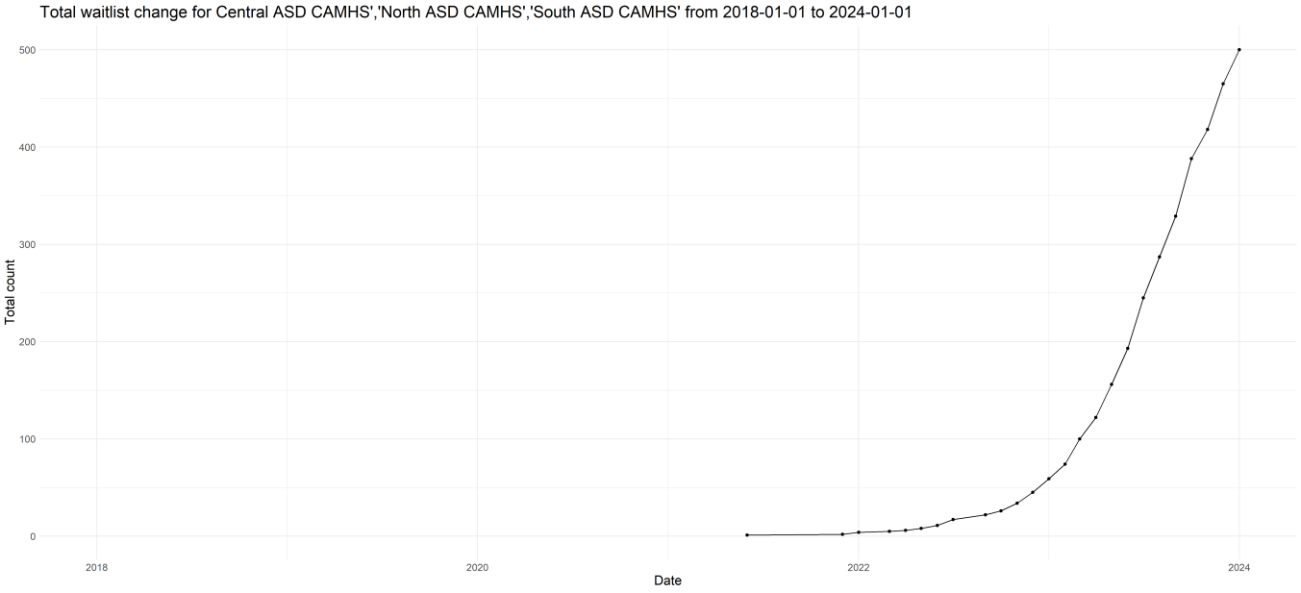


Note: this is only a partial picture, as these figures are only for children aged 11+ for autism services in Central and South Cambridgeshire CAMHS. They include under 11s for North CAMHS, but not referrals to community paediatrics (in CPFT or CCS) for pre-school and primary school children.

Service waiting lists

The total waitlist for children and young people's autism assessment services in Cambridgeshire and Peterborough showed a substantial increase from mid-2022 to 2023, to over 500 patients on the waiting list by the end of 2023.

Figure 27: Total waitlist for children and young people's autism assessment services, Central ASD CAMHS, North ASD CAMHS and South ASD CAMHS, January 2018 – December 2023. Data source: CPFT

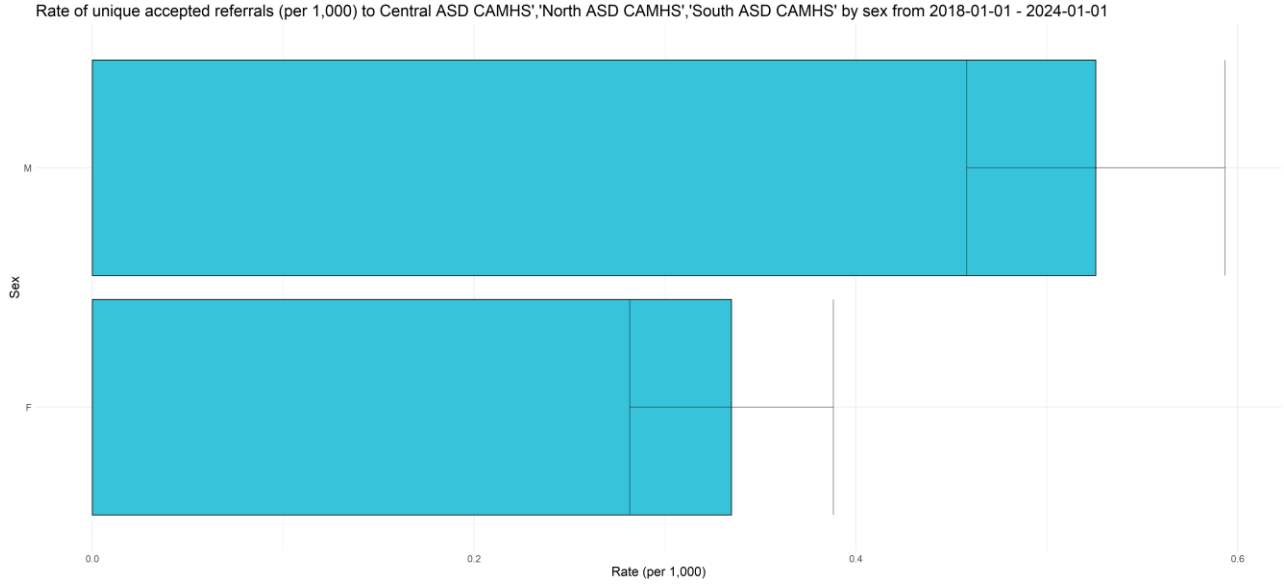


Note: this is only a partial picture, as these figures are only for children aged 11+ for autism services in Central and South Cambridgeshire CAMHS. They include under 11s for North CAMHS, but not referrals to community paediatrics (in CPFT or CCS) for pre-school and primary school children.

Referral rates by demographics

Between January 2018 and December 2023, boys were significantly more likely to be referred to children and young people's autism assessment services in Cambridgeshire and Peterborough than girls.

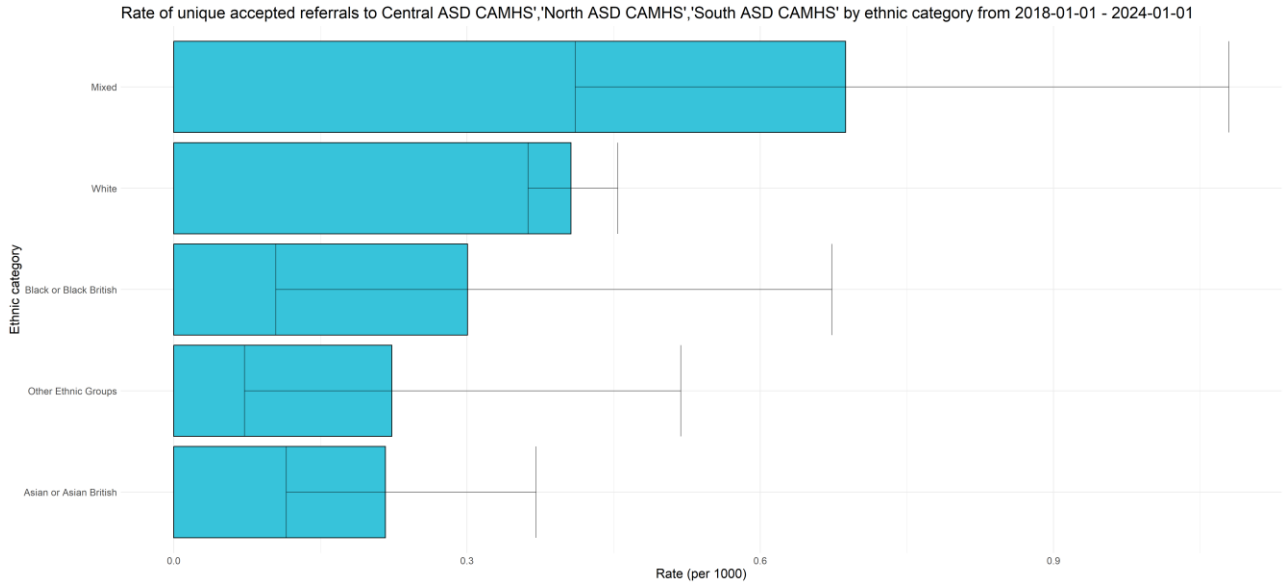
Figure 28: Referral rate per 1,000 by sex, Central ASD CAMHS, North ASD CAMHS and South ASD CAMHS, January 2018 – December 2023. Data source: CPFT



Note: this is only a partial picture, as these figures are only for children aged 11+ for autism services in Central and South Cambridgeshire CAMHS. They include under 11s for North CAMHS, but not referrals to community paediatrics (in CPFT or CCS) for pre-school and primary school children.

Over the same time period, the highest rate of referrals were for children and young people from 'Mixed,' and 'White' ethnic groups, and the lowest from 'Other' and 'Asian or Asian British' ethnic groups. The teams in children and young people's autism services are currently implementing the Patient Carer Race Equality Framework (PCREF) to try and understand this better.

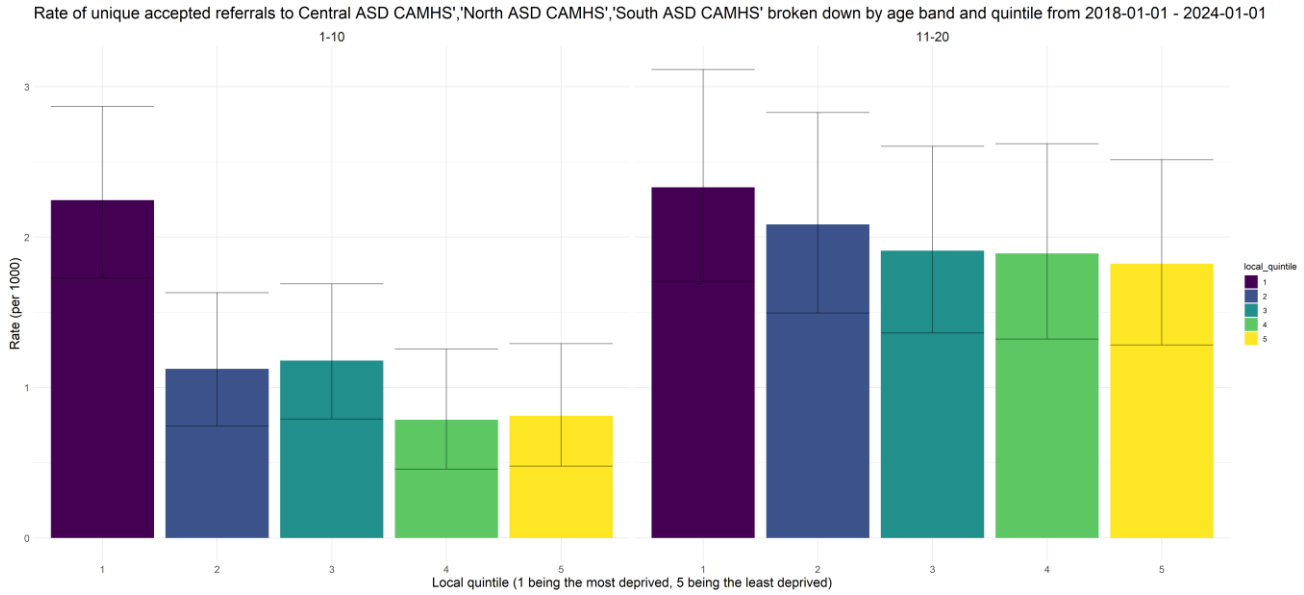
Figure 29: Referral rate per 1,000 by ethnicity, Central ASD CAMHS, North ASD CAMHS and South ASD CAMHS, January 2018 – December 2023. Data source: CPFT



Note: this is only a partial picture, as these figures are only for children aged 11+ for autism services in Central and South Cambridgeshire CAMHS. They include under 11s for North CAMHS, but not referrals to community paediatrics (in CPFT or CCS) for pre-school and primary school children.

Referral rates to children and young people's autism assessment services between January 2018 to December 2023 were highest in the most deprived areas in Cambridgeshire and Peterborough for children aged 0 - 10. There was not a significant different in referral rates across deprivation quintiles for children aged 11 – 20.

Figure 30: Referral rate per 1,000 by deprivation quintile, Central ASD CAMHS, North ASD CAMHS and South ASD CAMHS, January 2018 – December 2023. Data source: CPFT



Note: 1 indicates the quintile with the highest, and 5 the lowest, level of deprivation. This analysis only gives a partial picture as it is based on referrals of children and young people aged between 11 and 20.

Adults

Cambridgeshire Lifespan Autism Spectrum Service (CLASS) service offers a specialist diagnostic assessment for adults (18 years and over) who may meet the diagnostic criteria for autism without an intellectual disability. Referrals into this service are made through GPs, who refer people to the Primary Care Mental Health Service (PCMHS) where they receive an initial triage. Referrals can also be made via CPFT services.

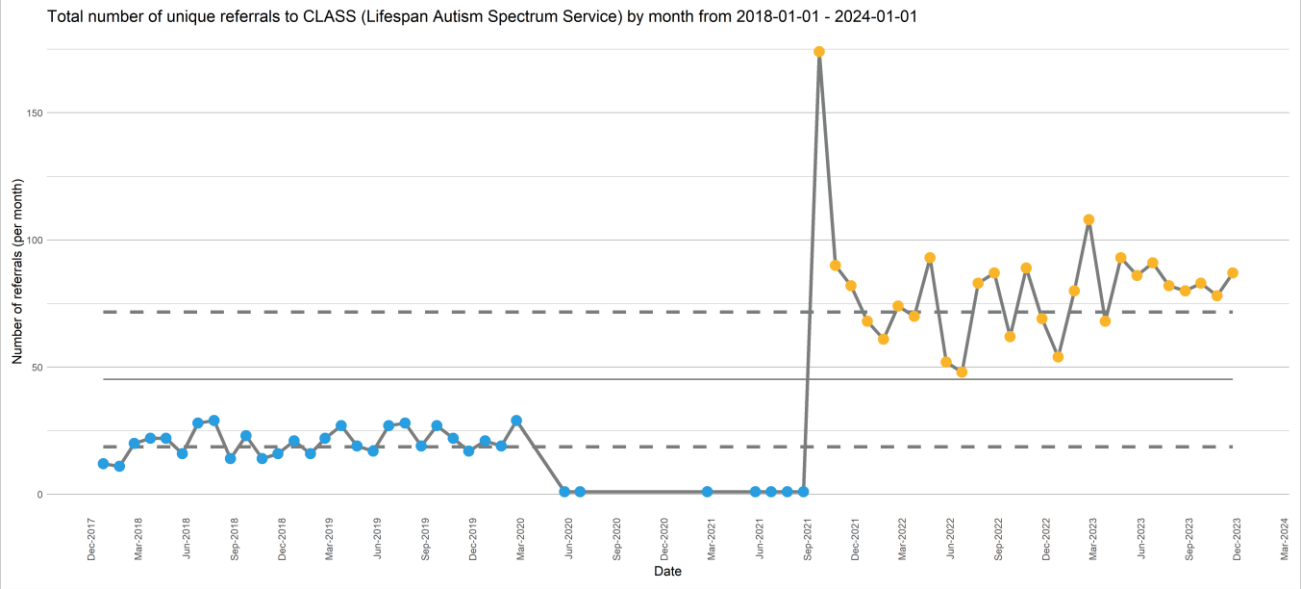
CLASS was closed to new referrals during the earlier stages of the COVID-19 pandemic (March 2020 – October 2021), which has contributed to an increase in waiting times.

Currently there is no joined up pathway between adult ADHD and autism assessment services in Cambridgeshire and Peterborough. If someone is identified as potentially having ADHD during their autism assessment, they can only access an assessment by joining the waiting list for Adult ADHD service.

Referral rates

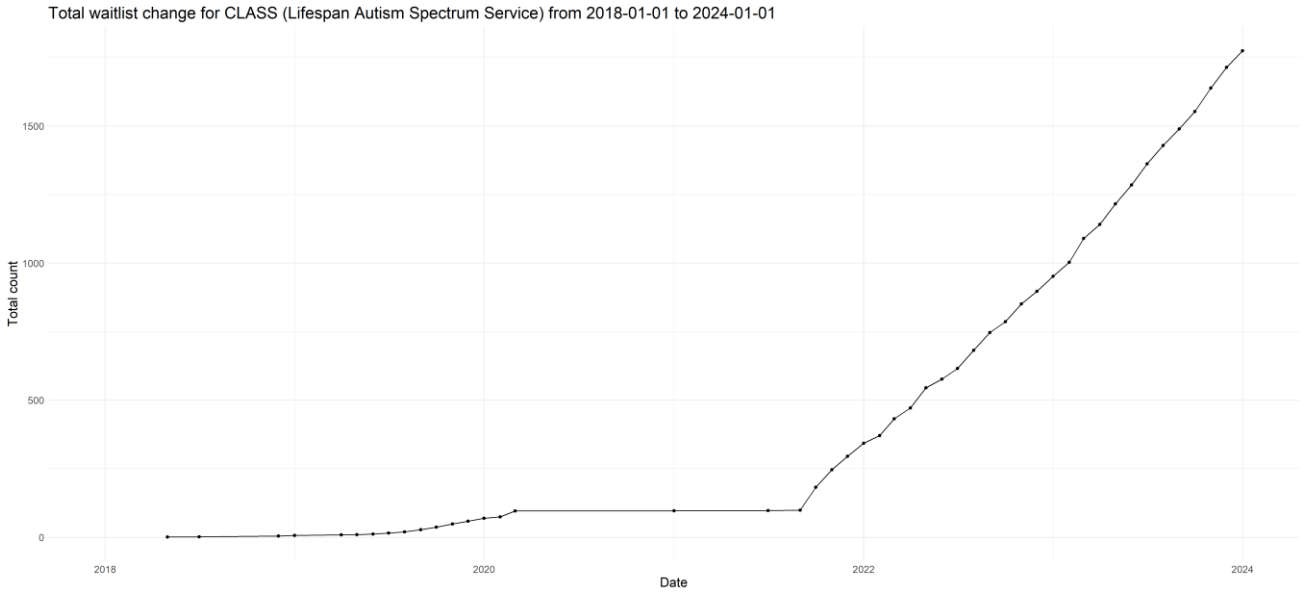
Since October 2021, there has a significant increase in the number of referrals to CLASS, from around 20 per month to 75 per month. The closure of this service in the early stages of the COVID-19 pandemic is likely to have contributed to this increase.

Figure 31: Referrals to CLASS, January 2018 – December 2023. Data source: CPFT



Since Septer 2021, there has been a substantial rise in the number of people on the waiting list for CLASS. By the start of 2024, this list included over 1,500 people.

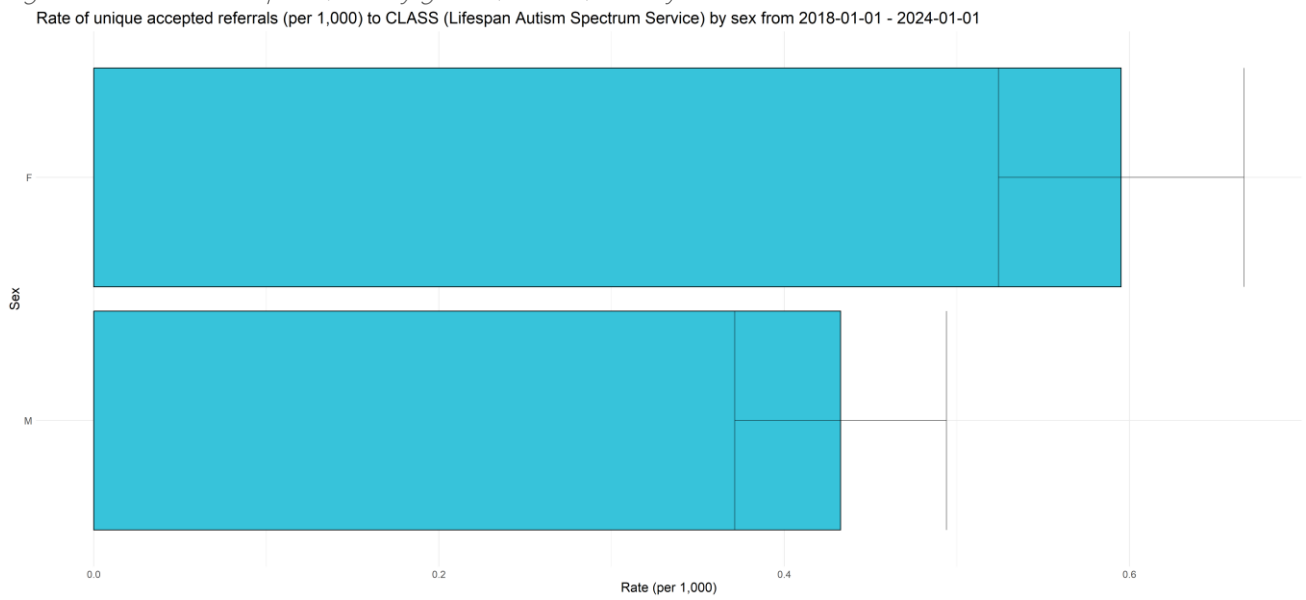
Figure 32: Total waitlist for CLASS, January 2018 – December 2023. Data source: CPFT



Referral rates by demographics

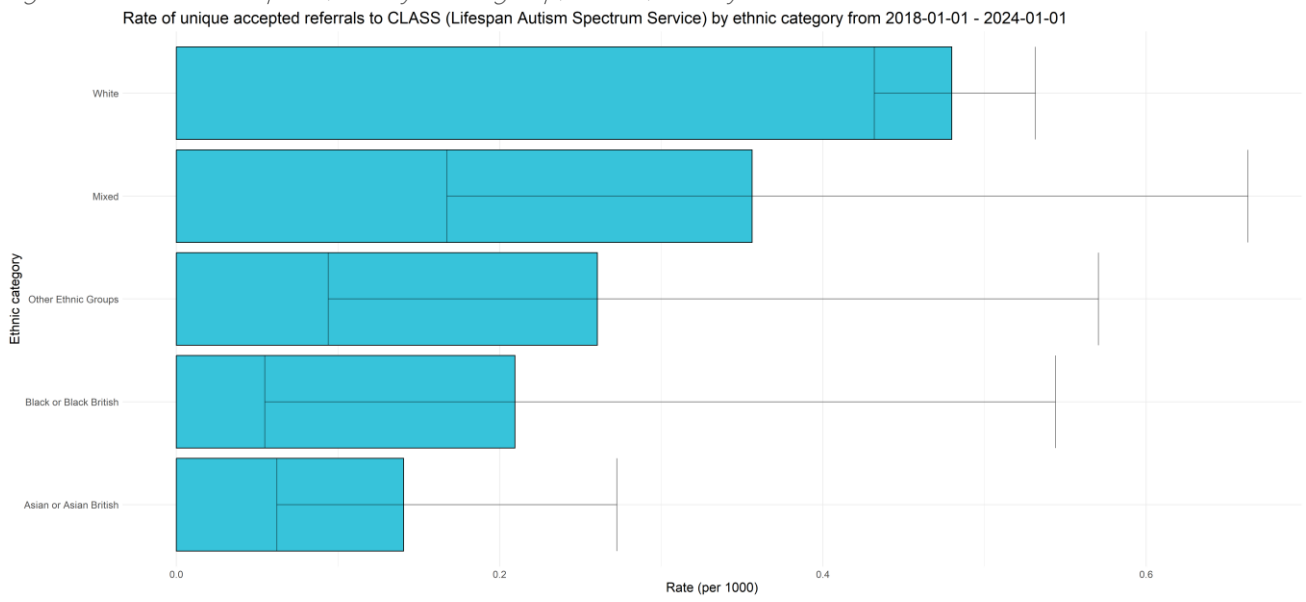
Between January 2018 to December 2023, a slightly higher rate of referrals to CLASS were for women.

Figure 33: Referral rate per 1,000 by gender, CLASS, January 2018 – December 2023. Data source: CPFT



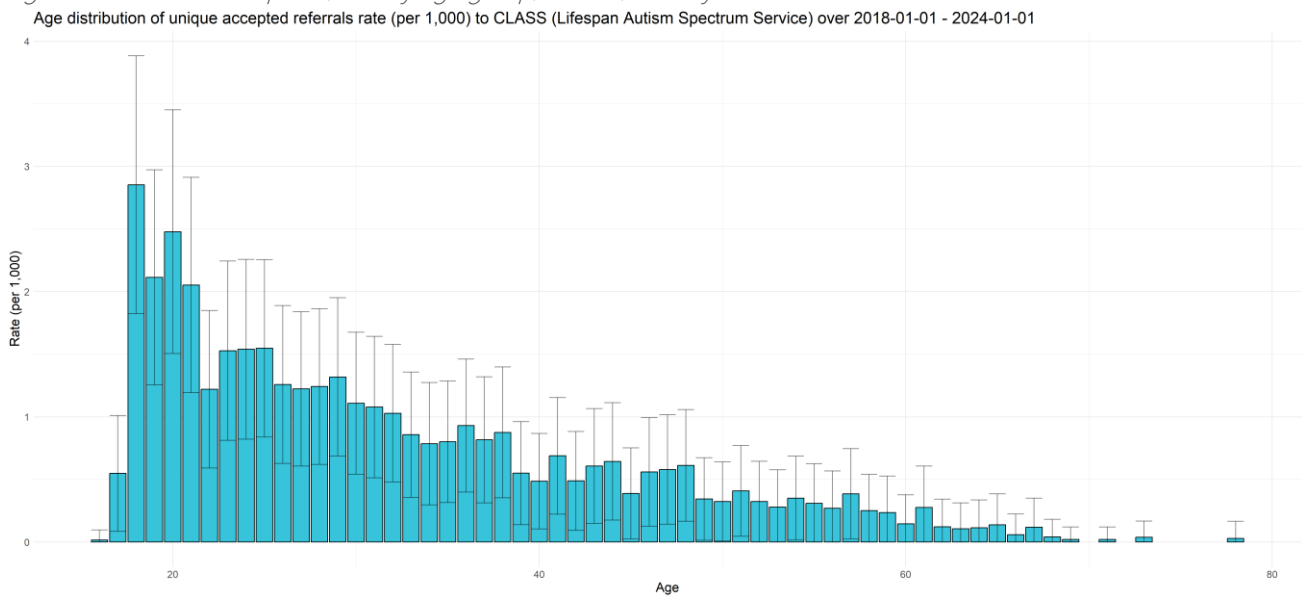
Between January 2018 and December 2023, a higher rate of referrals to CLASS were from people from a 'White' ethnic group, and a lower proportion from 'Asian or Asian British' ethnic groups. The trends for other ethnic groups are less clear.

Figure 34: Referral rate per 1,000 by ethnic group, CLASS, January 2018 – December 2023. Data source: CPFT



The highest rate of referrals to CLASS are from young adults aged between 18 and 21.

Figure 35: Referral rate per 1,000 by age group, CLASS, January 2018 – December 2023. Data source: CPFT



Post-diagnostic support

National literature highlights that many autistic people have limited post-diagnostic support (Jones et al., 2014; Ward, 2019). There is limited research evaluating different types of post-diagnostic support, however one study suggests that long-term low-intensity support such as drop-in services and peer-led groups for autistic adults may help to prevent future difficulties (Beresford et al., 2020).

CLASS offers post-diagnostic support for up to 6 months post-diagnosis. This includes psychoeducation groups; an opportunity to discuss diagnoses with a clinician; and access to books and leaflets about autism.

Alternative models and pathways

Some areas have introduced alternative models and pathways for both ADHD and autism assessments, including placing these services outside of mental health trusts. One alternative model is a needs-led approach, which focuses on addressing immediate needs before necessarily providing a clinical diagnosis. Another approach is integrated pathways for people requiring assessments of multiple neurodevelopmental conditions.

Needs-led approach

Needs-led services focus on early identification and providing faster support without relying on a diagnosis (Longfield, 2024). This is in contrast with the current model, in which people often have to have an assessment and clinical diagnosis before being able to access some types of support (e.g. in education). It has been suggested that this type of model may particularly benefit children and young people with sub-threshold ADHD symptoms (Kazda et al., 2024). One example of this approach has been designed in Portsmouth, where a Neurodiversity Team was developed:

- Families and professionals worked together to create a neurodiversity profiling tool, which can be used by a range of professional to identify strengths, skills and 'areas of challenge' which can be supported without a need for a clinical diagnosis.
- As well as this 'single point of contact', there is also an 'extended offer' of support for children and young people with more complex needs. This may include assessments, diagnosis and focused support.
- This approach has led to a substantial reduction in the demand for diagnostic services. However, as it was recently introduced, there is currently no data on the long-term outcomes of this approach.

Integrated neurodevelopmental pathway

An integrated neurodevelopmental pathway would combine assessment and support for ADHD, autism and other neurodevelopmental conditions (Male et al., 2023). This approach may help to address pathways people with multiple neurodevelopmental conditions currently navigate (Embracing Complexity, 2019; Male, Farr and Reddy,

2020). It also recognises that it is common for people to have multiple conditions: for example, one study found that 2 in 3 autistic children had traits of other neurodevelopmental conditions (Lang et al., 2024). One example of this is the Peterborough Integrated Neurodevelopmental Service.

Additional Resources

- A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards
- Guide to Complexity in planning for Assessment and Diagnosis of Neurodevelopmental Presentations
- An evidence-based plan for addressing the autism assessment and support crisis

Barriers and facilitators to effective mental health interventions

- There is a higher prevalence of mental illness amongst autistic people than the general population, and the number of children and adults with an autism diagnosis is rising across England. This means that autistic people make up a 'significant and fast-growing' group of patients supported by mental health services (NHS England, 2023c).
- Barriers to accessing healthcare are associated with poorer health outcomes in autistic people (Doherty et al., 2022) and improving access to healthcare has been identified as priority in surveys involving autistic people (Brede et al., 2022).
- People with ADHD can face barriers to accessing mental healthcare (Kappi and Martel, 2022). Flexible approaches to service delivery, such as appointment reminders, may help to improve healthcare access for people with ADHD (The Royal College of Psychiatrists in Scotland, 2023).

We recognise that people with different neurodevelopmental conditions can be at higher risk of experiencing mental health conditions (Sapiets, 2021), can share traits (such as sensory differences and difficulties with emotional regulation), and report that their mental health treatments do not take their neurodevelopmental condition/s into account (Autistica, 2019b). Improving the mental health system for people with ADHD and autistic people to have wider benefits for other neurodivergent people (Lord et al., 2022).

Barriers to accessing mental health interventions

Some barriers to accessing mental healthcare are common across a range of population groups (such as stigma around mental illness), whilst others may be specific to autistic people and people with ADHD.

Autistic people

A review of international research highlights that mental health services do not always provide effective support for autistic adults and can in some cases cause harm. The barriers that autistic people can face to accessing mental healthcare can result in inappropriate use of medication, pressures in their relationships where families and friends are relied on for support, and distrust in mental health services. This review highlights 'a need for a more flexible, comprehensive and holistic approach, considering how being autistic affects the individual's mental health presentation and tailoring support to their needs' (Brede et al., 2022).

This summary below is based on Brede et al.'s 2022 review. Many of these barriers can occur at any age, however some may change across the life-course, such as a specific lack of awareness of the health needs of older autistic adults (Malik-Soni et al., 2022). Parents and carers of autistic children can also face barriers to accessing support for their child, which can have a negative impact on their own mental health (Jackson, Keville and Ludlow, 2020).

Table 9: Barriers to accessing mental health services faced by autistic adults. Adapted from: Brede et al. 2022

Factors	Barriers to accessing mental health services
Structural	• Underfunding of mental health services for autistic people • Difficulties travelling to services (e.g. due to sensory overload on public transport) • Lack of research into the mental health needs of autistic adults
Healthcare system	• Professional's difficulties recognising symptoms of mental ill-health (e.g. assuming these were due to autism, rather than a mental health condition) • Complicated pathways to access support • Ineligibility for services due to autism diagnosis or being 'too complex' • Lack of support, training, knowledge and confidence of professionals to provide mental health interventions for autistic people • Inflexible or inappropriate service provision, which could lead to autistic people being perceived as 'not engaging' with care (e.g. autistic teenagers being transferred to adult services before feeling ready) • Lack of certainty about what therapy may involve • Over-reliance of standard self-reported mental health measures which may be unsuitable for some autistic people (e.g. due to atypical presentations of mental health conditions)
Individual	• Difficulties recognising the symptoms of mental ill-health • Previous poor experiences in mental health services, which can mean that some people lose trust in services

Some of the barriers listed above may stem from a lack of commissioned services, or siloed commissioning. For example, psychiatrists in the UK raise that long waiting lists, under resourced services, a lack of post-diagnostic support, and poor cross-system working leads to fragmented care for autistic people (Crane, Davidson, et al., 2019). Other barriers to them delivering effective support to their autistic patients included a lack of services for autistic adults who do not have an intellectual disability or mental health condition.

People with ADHD

There is limited research investigating if people with ADHD face specific barriers to accessing mental healthcare.

- A small study involving 30 adults with ADHD found that they reported facing 'an uphill struggle' to accessing services, particularly if they were diagnosed in adulthood, which had led to psychological distress, functional impairment and depressive mood in some people (Matheson et al., 2013). Key themes included:
    - Lack of understanding around adult ADHD from healthcare professionals
    - Struggles with the bureaucratic processes of accessing healthcare (e.g. stress associated with collecting medications every month, difficulties remembering to attend appointments)
    - Difficulties moving between child and adult mental health services.
- Some studies report that unrecognised ADHD may be associated with poorer adherence and/or responses to mental health treatment, for example due to forgetfulness (Barkley and Brown, 2008), whilst effective treatment of ADHD may help to manage mental health symptoms (Katzman et al., 2017).

One review looking at the barriers parents face in seeking out mental health interventions for children with ADHD identified that parents may not fully understand ADHD and the potential benefits of ADHD treatment, may face stigma around mental health conditions and struggle to seek out treatment when dealing with other issues, such as financial difficulties and parental mental ill-health (Kappi and Martel, 2022).

Factors	Barriers to accessing mental health services
Structural	• Transport and distance to healthcare service
Healthcare system	• Limited access to culturally competent services

Individual	• Parental mental healthcare seeking behaviours (e.g. due to past negative experiences with mental health services) • Lack of knowledge of ADHD, ADHD treatment and where to get support • Stigma

Additional Resources

- A Spectrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People

Facilitators to accessing effective mental health interventions

Facilitators are approaches that promote access and effective and appropriate mental health interventions. There are several NHS guidelines around improving the outcomes and experiences of autistic adults in mental health services. Some of these principles may apply for autistic people of all ages, as well as having wider benefits for people with ADHD and other neurodevelopmental conditions.

Some people who are autistic or have ADHD may not be aware of their condition/s, may not have (or be on the waiting list to receive) an NHS diagnosis, or may not feel comfortable sharing their diagnosis with healthcare professionals (Turnock, Langley and Jones, 2022). It is therefore important that approaches to improving care are not solely focused on people who have a clinical autism and/or ADHD diagnosis.

Guidelines

Recent reviews have identified strategies implemented within mental health services to improve mental health care for autistic children and young people (Pemovska et al., 2024), and adults (Loizou et al., 2023). These reviews highlight that, whilst there are gaps in evidence around effectiveness, greater knowledge of autism among healthcare professionals, providing adjustments, and some cognitive behavioural therapy (CBT) based interventions seem acceptable approaches to improving mental healthcare for autistic people.

Guidance for integrated care systems

In 2023, NHS England produced guidance for integrated care boards and wider system partners around meeting the needs of autistic adults in mental health services. These principles apply across all levels of mental health care, from support in the community, to planned mental health care, crisis care and inpatient services:

1) Ensure all services are accessible and acceptable to autistic adults: engagement and co-production of mental health services; reasonable adjustments

2) Support access to meaningful activity: healthcare professionals should support autistic adults to regularly engage in meaningful activities, including education, employment and leisure activities
3) Facilitate timely access to autism assessment, when clinically indicated: timely access to autism assessment may allow healthcare professionals to better meet autistic adults' mental health needs. Diagnostic overshadowing is an important related issue.
4) Use evidence to guide intervention choice: NHS care for autistic people should always be based on the best possible evidence, including the careful prescription of medication and evidence-based non-pharmaceutical interventions.
5) Assess and proportionately manage risk: careful consideration of risk formulation for autistic adults, balancing proactive risk-taking with recognising that autistic people are at a higher risk of suicide and self-injury.
6) Monitor and minimise the use of restrictive practices: ICBs should identify and reduce the level of restrictive practices used within community and inpatient services, including providing choices about treatment for autistic adults, avoiding overreliance on crisis intervention, effective transition planning and addressing high levels of seclusion and long-term segregation experienced by autistic adults.
7) Support cohesive transitions: supporting both diagnosed and undiagnosed autistic people over periods of transition, including transitions between services and life transitions.
8) Consider the physical health needs of people accessing mental health services: healthcare professionals should be aware of link between physical and mental health in autistic people.
9) Create a local commissioning strategy, informed by statistical data: ICBs should anticipate the likely growth in the number of people diagnosed as autistic and how many autistic people are likely to access mental health interventions.
10) Develop and maintain a well-trained workforce: develop and maintain the workforce needed to deliver high-quality care for all autistic people, such as by rolling out Oliver McGowan training and expanding the workforce.

There are also joint guiding principles for integrated care systems – learning disability and autism (2023), which set out how organisations can work to improve the lives and outcomes of autistic people and people with a learning disability.

Guidance for commissioners

There is a range of guidance around commissioning for autistic people.

- Supporting people with a learning disability and autistic people to live happier, healthier, longer lives: bitesize guide for local systems
- Commissioning services for autistic people: A cross-system framework for commissioning social care, health and children's services for autistic people and A framework for commissioning support for autistic people and their families
- A literature review on good learning disability and autism commissioning practice and impact
- The Royal College of Psychiatrists states that there should be 'explicit provision' in each area to provide mental healthcare for autistic people, which extends to people who do not have a clinical diagnosis or are on a waiting list for diagnosis (Royal College of Psychiatrists, 2020b).

NICE guidelines

There are NICE guidelines and quality standards for both autism and ADHD:

- Autism spectrum disorder in adults: diagnosis and management
- Autism spectrum disorder in under 19s: recognition, referral and diagnosis and support and management
- Autism quality standard for health and social care services
- Attention deficit hyperactivity disorder: diagnosis and management
- Attention deficit hyperactivity disorder quality standard for health and social care services

Evidence-based interventions

The Royal College of Psychiatrists has produced guidance around the management of autism in adults, the key points from which are summarised below:

- *'Therapies applied without awareness of the autism can be harmful or, at the least, ineffective'* and that therapists may need to make adjustments for autistic traits, such as using straightforward language and addressing sensory needs.
- Trauma-informed care is particularly important for supporting autistic people, as experiences of bullying and abuse are relatively common in autistic populations.
- Some autistic people can have increased or decreased sensitivity to psychotropic medications and may be more likely to experience adverse side effects.

Although there is limited research into mental health interventions specifically looking at the outcomes for autistic adults, and this research has rarely considered which interventions are acceptable to autistic people, some studies suggest that cognitive behavioural therapy (CBT) and mindfulness therapy may decrease symptoms of depression and anxiety in autistic populations (Linden et al., 2023). However, international research suggests that clinicians may be less likely to start cognitive behavioural therapy (CBT) with autistic patients as treatment for depression or anxiety, compared to non-autistic patients; and feel less confidence about its impact (Maddox et al., 2019).

Royal College of Psychiatrists guidance around ADHD in adults states that:

- All staff in community mental health services should be aware of 'core features of ADHD and the potential for a missed primary or comorbid diagnosis'.
- Treatment should 'include psychosocial interventions and be trauma informed', which is particularly important as people with ADHD are 'often bullied, feel they don't fit in, struggle academically and socially'.
- Flexible approaches may help to improve healthcare access for adults with ADHD, such as appointment reminders.

There is limited research into psychological interventions to improve the mental health of people with ADHD (Fullen et al., 2020). However, a lack of research into the effectiveness of some mental health interventions in people with ADHD or autistic populations is not evidence that these interventions are ineffective (Royal College of Psychiatrists, 2020a).

STOMP – STAMP

There is ongoing work nationally to improve the lives of autistic adults and children who are prescribed psychotropic medication, as part of Stopping Over Medication of People with a learning disability, autism or both (STOMP) and Supporting Treatment and Appropriate Medication in Paediatrics (STAMP).

Reasonable adjustments

- People who have an 'impairment that has a substantial and long-term adverse effect on your ability to do normal day-to-day activities' are considered disabled under the 2010 Equality Act and are entitled to ask for reasonable adjustments in public services, housing, education, work and healthcare services. This can include autistic people, people with ADHD and people with other neurodevelopmental conditions; including those who have not received a formal medical diagnosis (Citizens Advice, 2019).
- Studies involving autistic people highlight that access to adjustments is important in mental health services and that having a clinician who understands autism is the most important adjustment (Brice et al., 2021).
- Some autistic people report being unable to complete a course psychological therapy or missing healthcare appointments due to a lack of adjustments (Brice et al., 2021). Research also suggests that services may also discharge autistic people early due to perceptions that they 'fail to respond' to treatment, where adjustments have not been provided (Brede et al., 2022).
- A 'one size fits all' approach to reasonable adjustments is unlikely to work as autistic and people with ADHD have a wide range of communication abilities, sensory sensitivities and co-occurring health

conditions (Mason et al., 2019). These may need to be considered alongside other needs (e.g. language barriers, culturally sensitive care).

Sharing adjustments

There are two main ways of recording reasonable adjustments within the NHS, which can be used together:

- Health and care passports are a resource that contains information about the needs of patients, to support health and care staff to provide effective care. Each patient with a health and care passport should choose what they want to include, and who the passport should be shared with; and health and care staff should use the passport when providing support for individuals.
- The Reasonable Adjustment Flag was added to the NHS Spine in 2019, which allows professionals to record and view reasonable adjustments across different NHS services, where patient consent is given. The flag can adjustments around communications support, contact measures and adjustments to the environment, as well as any individualised reasonable adjustments. This is mandated for use in all care settings in England, as part of the NHS Long Term Plan; and must be fully implemented by the end of 2025. As of June 2024, this has not yet been rolled out in CPFT.

SPACE framework

The SPACE framework sets out 8 types of adjustments that may be useful for autistic patients: Sensory needs, Predictability, Acceptance, Communication and Empathy; as well as physical, processing and emotional space (Doherty, McCowan and Shaw, 2023). This framework was developed by a group of autistic doctors.

Figure 36: The autistic SPACE framework. Image source: Doherty et al. 2023

Examples of adjustments suggested in the SPACE framework are listed below:

Table 10: Reasonable adjustments in the SPACE framework. Adapted from: Doherty et al. 2023

Type of adjustment	Examples
Sensory	• Option to have dimmed or natural lighting • Avoiding highly stimulating décor (e.g. pinboard with lots of notices) • Promoting use of noise cancelling headphones • Avoiding highly scented cleaning products • Avoiding causal touch
Predictability	• Providing information in advance about the physical environment (e.g. photos on website) • Written agenda of therapy session • Option to have appointments at the same time each week

Acceptance	• Understanding of autistic stimming and thinking patterns • Facilitating the need for factual information
Communication	• Using of clear and direct language • Knowing that communication ability is reduced by anxiety and sensory stress • Avoiding phone-based appointment systems
Empathy	• Recognising that autistic people feel empathy but may display it differently • Relating to an individual's interests
Space: Physical	• Avoiding casual touch • Allowing for a need for increased personal space
Space: Processing	• Allowing for increased time to respond to questions • Allowing for increased time for decision making
Space: Emotional	• Accepting differences in emotional expression

Information and communication

- The Accessible Information Standard addresses people's information needs. This was developed by NHS England and defines a specific approach to meeting the information and communication needs of people using NHS and adult social care services, where these needs relate to a disability, impairment or sensory loss (including people who are d/Deaf, blind or deafblind). It may also be relevant to people who are autistic or whose mental health conditions impacts their ability to communicate.
- One study involving autistic adults found that written communication such as email and text messaging was the preferred way of accessing services, as this provides structure, allows for more thinking time and reduces sensory issues and anxiety (Howard and Sedgewick, 2021). In this study, many autistic people reported that making and receiving phone calls is their least preferred type of communication.
- The National Autistic Society has an accessible information guide and an autism-friendly checklist for services.

Physical environment

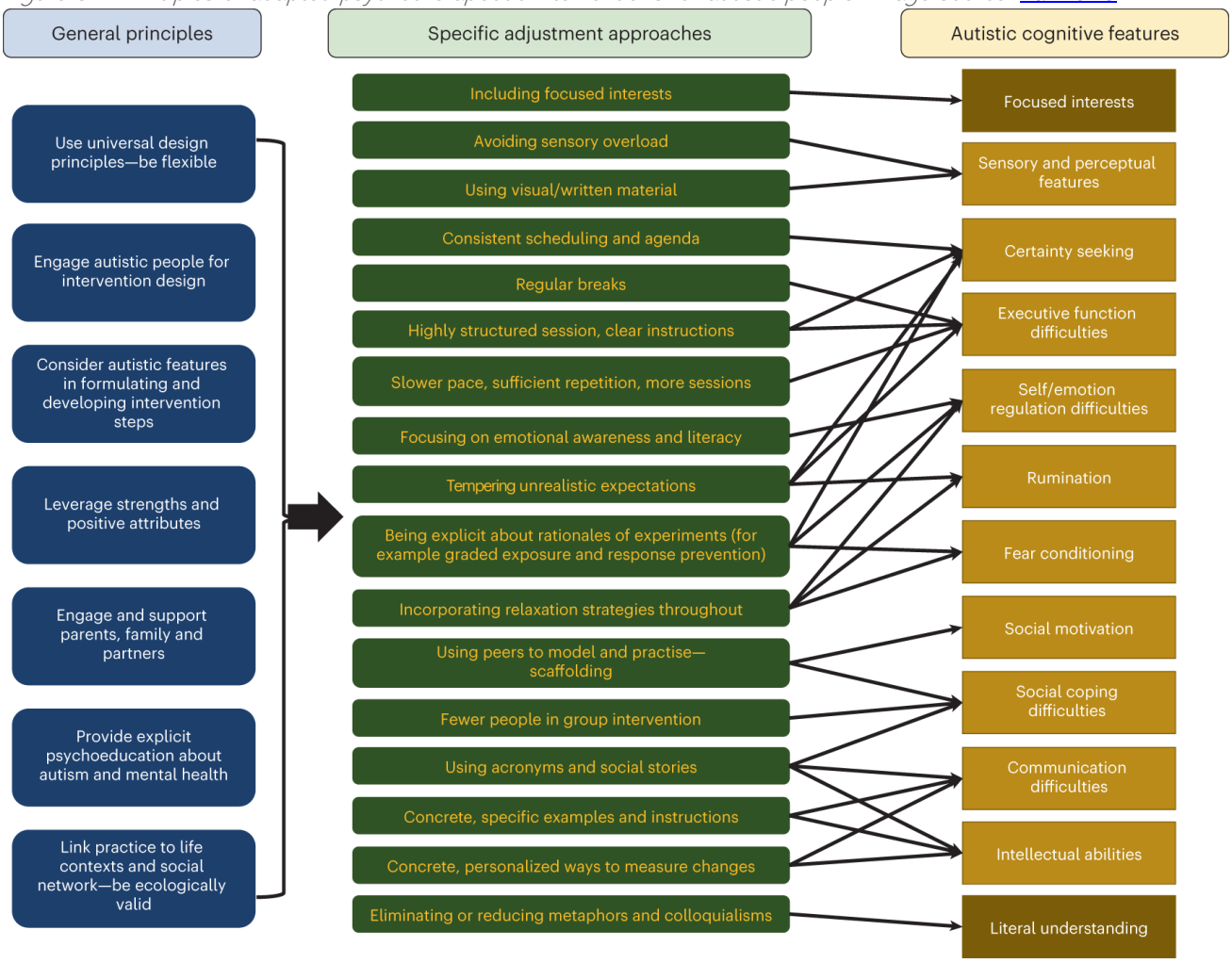
Sensory differences are common amongst people with ADHD and autistic people, with an estimated 70% to 90% of autistic people having sensory sensitivities (Ghanizadeh, 2011; NHS England, 2023e). This can include hyper-sensitivity (over-reactivity to sensory input), hyposensitivity (under-reactivity to sensory input) and sensory seeking (unusual interest in aspects of the sensory environment). To meet this wide range of needs, it has been suggested that services 'focus on ensuring access to a range of environments' and providing information to allow people to make informed decisions (Autistica, 2019a).

The NHS states that environments that do not have adaptations for autistic people's sensory needs can 'impede the effectiveness, or hamper the delivery of, therapeutic intervention, exacerbate poor mental health and lead to the use of restrictive practices such as restraint, seclusion or segregation' (NHS England, 2023e). NICE guidelines recommend that healthcare professionals should consider making adaptations to the physical environment, such as considering the lighting and noise levels, to provide effective care for autistic adults (NICE, 2022).

Psychotherapeutic interventions

There are a range of evidence-based adaptations to psychotherapeutic interventions for autistic people (Lai, 2023). These are summarised in the diagram below, which lists general principles (on the left), and approaches to adjustments (middle) which can be used to address barriers associated with autistic cognitive features (right). For example, around half of autistic people have difficulties identifying their emotions (alexithymia) (Kinnaird, Stewart and Tchanturia, 2019). As a result, it may be useful for clinicians to focus on emotional awareness with some autistic patients.

Figure 37: Principles of adapted psychotherapeutic interventions for autistic people. Image source: Lai 2023



Autism Toolkit

The Autism Toolkit was created as part of the Cambridgeshire and Peterborough All-age Autism Strategy. It is a self-assessment tool which encourages and supports organisations to become more accessible and includes 5 standards around:

1) Environment: ensuring that the physical environment is accessible to children, young people and adults with autism. This includes adjustments that can be made to virtual environments.
2) Training: ensuring that providers of public services follow the 'Statutory guidance for Local Authorities and NHS organisations to support implementation of the Autism Strategy to help improve the delivery of the services'
3) Communication Methods: ensuring that providers/organisations are aware and understand how to communicate with service users and should ensure accessible formats are available. This includes an acknowledgement that behaviour is a form of communication.
4) Integration of Services: ensuring service providers/organisations have an understanding of the wider service offer, fostering relationships between internal and external providers/services
5) Communications/Marketing: ensuring all services available for those with an autism diagnosis are appropriately communicated, using a variety of platforms and accessible channels

Additional Resources

- The NHS Reasonable Adjustment Flag, including a case study, training and action checklist
- Centre for ADHD and Autism Support's Reasonable adjustment menu
- The national Think Autism Strategy, published in 2016, sets out good practice in delivering reasonable adjustments
- An independent guide to quality care for autistic people
- Sensory-friendly resource pack and Sensory-friendly resource pack: Resources to improve the sensory environment for autistic people
- Checklist for Autism-Friendly Environments
- 10 priority recommendations for how inpatient wards can be improved for autistic people. This list for Sensory Friendly Wards was developed from research on the experiences of children and young people who have used child and adolescent mental health services (CAMHS) inpatient environments.
- Principles of adapted psychotherapeutic interventions for autistic people
- Supporting autistic children and young people through crisis
- Sensory processing needs toolkit: provides guidance for practitioners to support children with sensory needs
- Neurodiversity and autism resources collated by Coventry and Warwickshire ICS

Workforce

NHS guidelines state that all statutory bodies within ICBs should develop and maintain their workforce to provide high-quality mental health interventions for autistic adults. This includes developing autism knowledge of the whole workforce through Oliver McGowan training; upskilling, expanding and retaining the workforce that cares for autistic people; and workforce planning and transformation (NHS England, 2023c). Literature highlights the importance of recognising that organisational factors, such as waiting lists and referral pathways, contribute impact clinicians' ability to provide effective care for autistic people (Coughlan et al., 2020).

There is currently no NHS guidance around developing the workforce to support people with ADHD.

Training

NICE guidelines state that 'all health and social care professionals providing care and support for autistic adults should have a broad understanding of the nature, development and course of autism' (NICE, 2022). The Health and Care Act 2022 included a statutory requirement that regulated service providers ensure staff receive training around autism and learning disability, that is suitable for the requirements of their role (NHS England, 2024b). The Oliver McGowan Mandatory Training was developed for this purpose.

- Tier 1 of the Oliver McGowan training is an e-learning course for people who require general awareness around autism and learning disabilities (including staff in non-public facing roles). This is compulsory for all CPFT staff. Tier 1 also includes an hour-long webinar with opportunities to meet and talk to a learning disabled and an autistic lived experience expert.
- Tier 2 of the Oliver McGowan Training is a 1 day of face-to-face training delivered by trainers and experts with lived experience. In Cambridgeshire and Peterborough, a network of community organisations with considerable experience of working with autistic and learning disabled people is delivering the training that has been jointly developed and co-produced by Mencap and the National Autistic Society. The Cambridgeshire and Peterborough network includes the following training organisations:
    - the Community Interest Company The Expert On Myself (TEOM)
    - the Community Interest Company Safe Soulmates
    - Eddies, a charity under the umbrella of The Edmund Trust

- The charity Circles Network
- Advocacy charity Voiceability

Examples of training include:

- Oliver McGowan Mandatory Training
- National Autism Training Programme for Psychiatrists
- The role of general practitioners in ADHD diagnosis and management
- A guide to the mental health experiences and needs of autistic teenagers
- Autism Awareness E-learning (only available for CPFT staff)
- Experts On Our Autism and Experts On Our Neurodiversity training by lived experience trainers, tailored to individual organisations, through The Expert On Myself (TEOM)

A recent review identified several approaches to training mental health staff to provide better care to autistic people, (Pemovska et al., 2024). Although before- and after- comparisons showed significant improvements in staff knowledge after training, findings were limited by limited by small sample sizes and a lack of comparison groups.

Understanding of autism and ADHD among healthcare professionals

- A recent review found that primary care clinicians can lack of training or confidence around ADHD, and that this can be a barrier to the recognition of ADHD within primary care (French, Sayal and Daley, 2019).
- National surveys suggest that many psychiatrists are knowledgeable about autism and have received some training on autism (Crane, Davidson, et al., 2019). However, a national survey carried out in 2017 found that 40% of GPs had never received formal training about autism, and that whilst many had a good knowledge of the key features of autism, most did not feel confident in identifying and supporting autistic patients (Unigwe et al., 2017).
- Another national survey, carried out in 2019, found that autistic people and their families felt that most professionals do not have a good understanding of autism, although mental health professionals scored most highly in terms of perceived understanding of autism (APPGA, 2019).

Figure 38: Professional understanding of autism, as reported by autistic people and their families. Image source: The Autism Act, 10 Years On

Additional Resources

- Oliver's Campaign
- Core Capabilities Framework for Supporting Autistic People
- National Autism Trainer Programme (NATP)
- The Capability Framework for Autism Peer Support Workers

Survey of local services

As part of this chapter of the mental health needs assessment, we carried out a survey of local services providing mental health support, to better understand the strengths and gaps in how mental health services provide support to autistic people and people with ADHD.

This survey was sent out widely in June 2024, to staff in CPFT as well as hospitals and voluntary and community sector (VSC) organisations.

How was this survey developed?

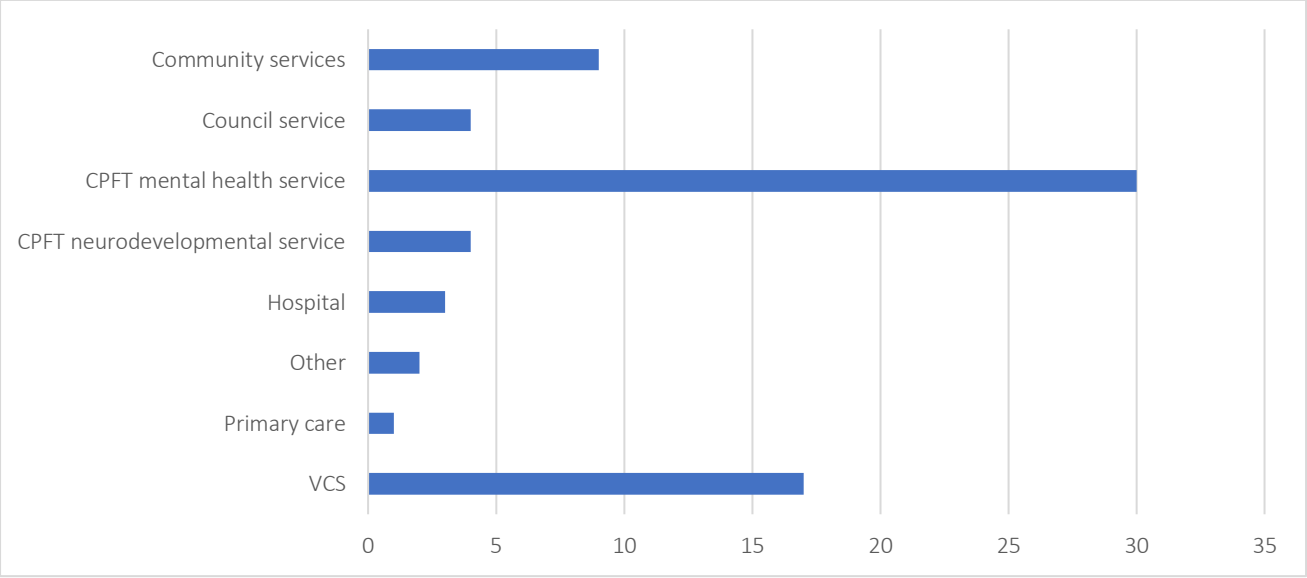
This survey is based on the Green Light Toolkit, which was commissioned by NHS England in 2022. This toolkit was created by the National Development Team for Inclusion, who worked with autistic people and NHS staff to develop the questions.

We added questions around ADHD and have included ADHD in some questions to this toolkit, as we recognise that people with ADHD may face specific barriers to accessing mental healthcare. We also acknowledge that many people have both autism and ADHD, and that autism and ADHD can share overlapping traits that may impact how people interact with and experience mental health services (e.g. sensory differences).

Who completed this survey?

The survey had 70 responses from staff in a range of services, although most worked in either CPFT mental health services (43%) or VSC organisations (24%).

Figure 39: Survey respondents by service type



Full detailed about which services were included are listed below:

Table 11: Survey respondents by service name and type

Service type	Respondents
Community services	Emotional Health and Wellbeing Service; Mental Health Support Team

Council service	Cambridgeshire County Council; Healthy Child programme; Social services (mental health)
CPFT mental health service	CAMEO; CAMHS; Home Treatment Team; Personality Disorder Team; Recovery Coach Team; S3; Specialist mental health services (not specified); Talking Therapies; Older people's mental health services; Primary care mental health service
CPFT neurodevelopmental service	Adult ADHD Service; CAMHS Neurodevelopmental Service; Learning disability and adult ADHD; Peterborough Integrated Children's Service
Hospital	Cambridge University Hospitals (Paediatric Psychological Medicine); NWAFT (including in the emergency department)
Other	Had worked in multiple roles (CPFT, ICS and GP); Windsor Research Unit
Primary care	Primary care (role not specified)
VSC organisation	Cambridge Women's Resources Centre; Cogwheel Counselling; CPSL Mind; Lifecraft; Nessie In Ed; Peterborough Counselling Ltd; The Kite Trust; The Red Hen Project

Key findings: service provision

The table below summarises the results from the 33 questions on service provision, each of which had 4 options. The table below gives a snapshot across multiple services, by showing the most common response (the answer selected by the greatest number of respondents). Each question was given a score between 0 and 100, where 100 indicates the best response. This gives a sense of the spread of different answers, as it was calculated from the mean score (where option 1 gave a score of 0 and option 4 gave a score of 100).

Question	Most common response	Score
Safeguarding - autism	The mental health service is also learning and changing its practice in response to local incidents that involve autistic people.	72
Safeguarding - ADHD	The mental health service is also learning and changing its practice in response to local incidents that involve people with ADHD.	70
Staff attitudes - autism	Mental health staff have improved their response to autistic people and continue to learn and make adjustments.	68
Thriving - autism	It is evident that mental health staff take a positive attitude towards autistic people as neighbours, friends and partners, students and employees, voters and contributors to wider society.	68
Thriving - ADHD	Mental health staff support people ADHD and people to learn more safe ways to tell others about their interests and differences, express their feelings and find information and support.	68
Self-regulation	Mental health staff provide opportunities for autistic people and people with ADHD to learn about self-management and actively encourage it.	66
Staff attitudes - ADHD	Mental health staff have improved their response to people with ADHD and continue to learn and make adjustments.	64
Personal care*	It's a problem every time someone arrives in mental health services and needs help with personal care, whether this is due to learning or physical disability, dementia, sensory differences or other reasons.	61
Eligibility and access - autism	Some autistic people may receive support from our mental health services, but this is not part of a deliberate and systematic approach	55
Eligibility and access - ADHD	Some people with ADHD may receive support from our mental health services, but this is not part of a deliberate and systematic approach	54
Reasonable adjustments - ADHD	A few things have been done to support individuals, but they do not really affect everyday practice in mental health services.	49
Harmful behaviour - autism	Mental health staff respond well to distress and help the person to find a positive way to manage the emotions, thought processes and environments that can drive harmful behaviour.	49
Harmful behaviour - ADHD	Mental health staff respond well to distress and help the person to find a positive way to manage the emotions, thought processes and environments that can drive harmful behaviour.	49
Reasonable adjustments - autism	A few things have been done to support individuals, but they do not really affect everyday practice in mental health services.	48

Physical health - ADHD	There is some understanding that people with ADHD may have extra health needs including other health conditions, issues related to ADHD medication, and risks of misdiagnosis.	46
Skilled workforce - autism	Our mental health service has limited effectiveness with autistic people because we lack knowledge and skills	44
Physical health - autism	There is some understanding that autistic people may have extra health needs including other health conditions, issues related to self-assessment and reporting, and risks of misdiagnosis.	43
Therapies - ADHD	People with ADHD have the same access to therapy as others using the mental health service.	43
Accessible information	Some general information is available, perhaps on the mental health service's website, but there is no evidence that it is being used.	42
Assessment - autism	Mental health staff also carry out a person-centred assessment that avoids stereotyping, promotes social, emotional, cultural, spiritual and physical wellbeing and recognises the possibility that the person may be autistic.	42
Skilled workforce – ADHD	Our mental health service has limited effectiveness with people with ADHD because we lack knowledge and skills	42
Assessment - ADHD	Mental health staff also carry out a person-centred assessment that avoids stereotyping, promotes social, emotional, cultural, spiritual and physical wellbeing and recognises the possibility that the person may have ADHD.	41
Health and care records	Health and care records are standardised for everyone and the proforma must be used in the same way for everyone.	40
Therapies - autism	Autistic people have the same access to therapy as others using the mental health service.	40
Employment support - autism	Specialist mental health employment supports (such as internships, job coaching and IPS services) are available to autistic people.	38
Employment support - ADHD	Specialist mental health employment supports (such as internships, job coaching and IPS services) are available to people with ADHD.	38
Co-production – autism*	The mental health service talks about coproduction, but not many autistic people are involved.	37
Co-production – ADHD*	The mental health service talks about coproduction, but not many autistic people are involved.	36
Working together - autism	A few staff working in mental health services know colleagues in other teams and this helps to coordinate joint work across mental health teams, primary care, social care, education, criminal justice, out of hours and crisis services.	35
Support for family and friends - ADHD	Family and friends of people with ADHD are involved in care planning where restrictions permit and the person wishes it.	34
Support for family and friends - autism	Family and friends of autistic people are involved in care planning where restrictions permit and the person wishes it.	32
Working together - ADHD	A few staff working in mental health services know colleagues in other teams and this helps to coordinate joint work across mental health teams, primary care, social care, education, criminal justice, out of hours and crisis services.	32
Buildings and environment	Autistic people and people with ADHD are expected to use the same buildings in the same way as everyone else.	18

**Almost a third of people did not respond to these questions. Comments suggest that some people did not respond when the question was not relevant to their service (e.g. their service was not appropriate for people who require personal care) or they did not know enough to answer the question (e.g. they were unfamiliar with the term co-production or were not involved with this in their service).*

Based on this scoring, the areas which rated highest and lowest in terms of provision for autistic people and people with ADHD were:

Highest scoring	Lowest scoring
1) Safeguarding – autism 2) Safeguarding – ADHD 3) Staff attitudes – autism 4) Thriving – ADHD	1) Buildings and environment 2) Support for family and friends – autism 3) Working together – ADHD 4) Support for family and friends – ADHD

5) Thriving – autism	5) Working together – autism

Key findings: comments

Survey respondents had an option to leave a comment, which included:

- Several services reported that they had 'specialists' in autism and ADHD (such as staff who had completed additional training, had done research in their own time or who are neurodivergent themselves), but that not all staff shared this level of expertise. This could lead to support being 'hit and miss'.
- Many people felt they would benefit from more training around autism and ADHD, including low cost or free training for VSC organisations.
- A lack of data collection/recording could mean it was difficult to understand what was happening (for example, if current co-production work involves people with ADHD, or if autistic people are more likely to experience safeguarding concerns).
- The question around the built environment was not relevant for services who deliver support online.
- Some people highlighted a need for specialist support for patients with both autism and ADHD.

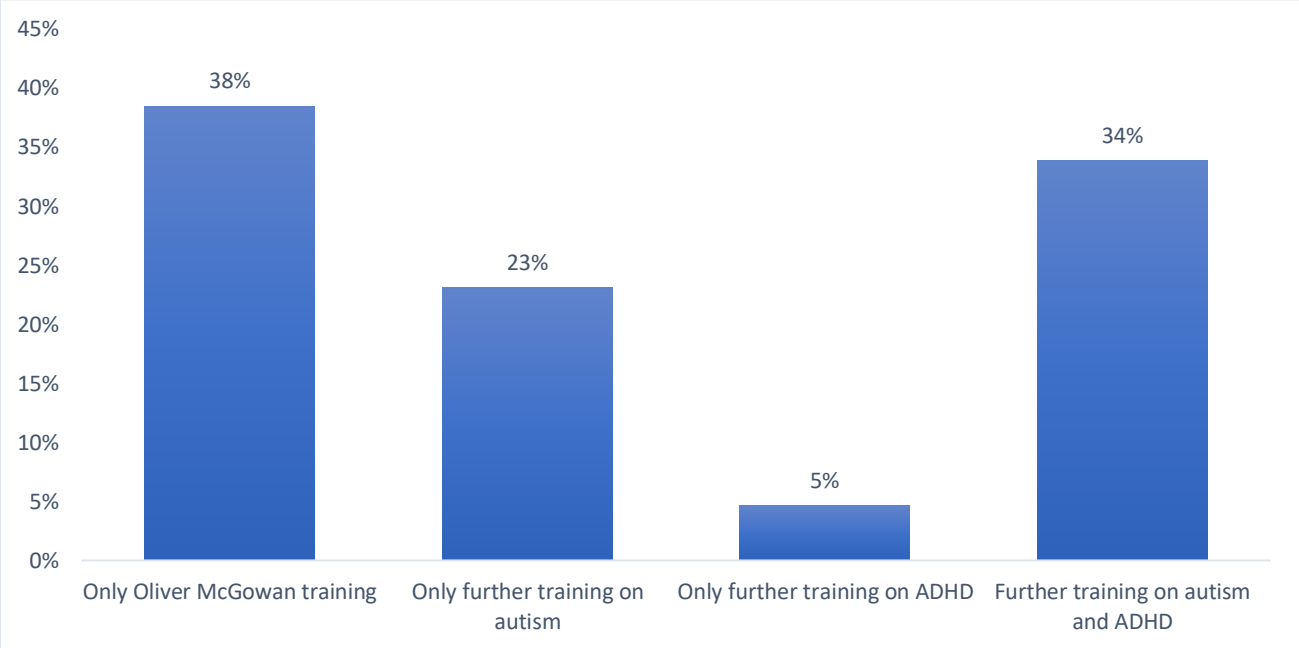
Respondents working with children and young people could also leave specific reflections about working with this age group. Some people felt that:

- Mental health provision for children and young people can be 'too rigid', for example a lack of adjustments in therapies which meant that children were unable to engage, or a lack of parenting courses providing tailored information for parents of neurodivergent children.
- There is a need for a new 'early intervention' service to support children and young people presenting with neurodiversity, which could include skills training for professionals.
- Social issues are key when supporting young people (e.g. school avoidance, learning to be social).

Key findings: training

There was a mixed picture as to the training of staff: 38% of respondents reported having completed Oliver McGowan training, but not any additional training around autism of ADHD; whilst 34% had completed further training around both autism and ADHD.

Figure 40: Training reported by survey respondents.



Note that, at the time of this survey, Cambridgeshire and Peterborough ICS had not implemented the roll out of Tier 2 of Oliver McGowan mandatory training. These results therefore only relate to Tier 1 Oliver McGowan Training.

Key findings: system strengths and gaps

A set of questions were sent to 3 system leaders in the integrated care board to identify strengths and gaps in in leadership, local planning, monitoring and restrictive practice. Full results are listed below, with responses highlighted in grey.

Autism

Leadership			
We don't know who is interested in improving mental health services for autistic people.	We know which staff, people using services and relatives want to improve mental health services for autistic people.	Autistic leaders, family leaders and staff leaders have been identified to improve mental health care for autistic people.	There is a plan for improving mental health care for autistic people
Local plans			
Services are not joined up, so autistic people miss out because services are missing, unsuitable or not aligned.	The Joint Strategic Needs Assessment, local Health and Wellbeing strategy and commissioning plans include the mental health needs of autistic people throughout the life-course.	Long term outcomes are tracked to ensure that autistic people are receiving good support from mental health services and to reduce the chance of adverse events, such as unemployment or homelessness, imprisonment or premature death.	National and local evidence is fed into plans for improving services.
Restrictive practice			
There are autistic people in our area who are in prison and locked mental health units, detained under the Mental Health Act or subject to Liberty Protection Safeguards - but we don't know much about them or if they are in the best place.	There are autistic people in our area who are in prison and locked mental health units, detained under the Mental Health Act or subject to Liberty Protection Safeguards - but we don't know much about them or if they are in the best place.	Places where people are detained have minimised restrictive practices whilst keeping everyone safe, including a review of formal and informal rules that are applied to everyone, such as access to the internet or time to be alone.	Mental health services work with Probation and other agencies to support autistic people to obey the law, become more independent and leave behind environments that detain and restrict them.

ADHD

Leadership			
We don't know who is interested in improving mental health services for people with ADHD.	We know which staff, people using services and relatives want to improve mental health services for people with ADHD.	People with ADHD, family leaders and staff leaders have been identified to improve mental health care for people with ADHD.	There is a plan for improving mental health care for people with ADHD.
Monitoring			
Our local data on the number of people with ADHD using mental health services is inaccurate or out of date	A spot check of Electronic Patient Records has been done recently to find out about people with ADHD using the mental health service, but we do not routinely collect or regularly analyse this.	Data on people with ADHD using mental health services is routinely collected via the Electronic Patient Record system. Results are compared with the census and national benchmarks.	Unwarranted variations in access and outcomes data for people with ADHD lead to improvements in the mental health service.
Local plans			
Services are not joined up, so people with ADHD miss out because services are	The Joint Strategic Needs Assessment, local Health and Wellbeing strategy and commissioning plans include	Long term outcomes are tracked to ensure that people with ADHD are receiving good support from	National and local evidence is fed into plans for improving services.

missing, unsuitable or not aligned.	the mental health needs of people with ADHD throughout the life-course.	mental health services and to reduce the chance of adverse events, such as unemployment or homelessness, imprisonment or premature death.	
Restrictive practice			
There are people with ADHD in our area who are in prison and locked mental health units, detained under the Mental Health Act or subject to Liberty Protection Safeguards - but we don't know much about them or if they are in the best place.	There are people with ADHD in our area who are in prison and locked mental health units, detained under the Mental Health Act or subject to Liberty Protection Safeguards - but we don't know much about them or if they are in the best place.	Places where people are detained have minimised restrictive practices whilst keeping everyone safe, including a review of formal and informal rules that are applied to everyone, such as access to the internet or time to be alone.	Mental health services work with Probation and other agencies to support autistic people to obey the law, become more independent and leave behind environments that detain and restrict them.

Mental health interventions

- Both autistic people (Brede et al., 2022) and healthcare professionals (Crane, Davidson, et al., 2019) raise that autistic people with mental health conditions can find it difficult to access support from both mental health services and autism-specific services.
    - A national survey carried out in 2019 found that 76% of autistic adults had reached out for mental health support in the preceding 5 years, and that only 14% of autistic adults felt there were enough mental health services in their area to meet their needs (APPGA, 2019).
- Although evidence suggests that people with ADHD are overrepresented in mental health services, there is limited research into the access and outcomes of people with ADHD within mental health services.

The sections below detail what we know about the mental health support for autistic people and people with ADHD across different age groups, recognising that the needs of these groups may change over people's lifetimes.

Perinatal

Previous chapters of the mental health needs assessment highlight that the perinatal period (pregnancy, birth and the first two years of a child's life) is a key period and that mental health conditions that occur during this time can have a particularly strong negative impact on parents and families. There is limited research into the mental health needs of parents with ADHD and autistic parents during the perinatal period.

- One study found that autistic parents had higher rates of pre- and post-partum depression than non-autistic mothers and were more likely to feel misunderstood by healthcare professionals (Pohl et al., 2020). Another small study found that autistic women reported higher levels of depression and anxiety symptoms and greater stress during the perinatal period, compared to non-autistic women (Hampton et al., 2022).
- There is little research into the mental health needs of parents with ADHD (Kittel-Schneider et al., 2021). One meta-analysis suggested that ADHD is associated with a greater risk of teenage pregnancy (Kittel-Schneider et al., 2021), which can be associated with poor mental health.

Children and young people

An earlier chapter of the mental health needs assessment explores the mental health needs of children and young people in Cambridgeshire and Peterborough across four stages in their lives: preschool, primary school, secondary school and entering adulthood.

- There are substantial capacity issues in children and young people's mental health services across England. Autistic children and children with ADHD face long waiting times for NHS support and diagnostic assessments, which can have a negative impact on their mental health and wider outcomes (J. Smith, 2023). In England:
    - Children and young people referred to mental health services for the primary reason of 'suspected autism' face the longest wait to accessing services (median wait of over 7 months), followed by children with 'other neurodevelopmental conditions' (median wait of 3.5 months) (Children's Commissioner, 2024).
    - By service type, the longest waits are for 'Autism Services' (median wait of around 16 months) and 'Neurodevelopment Teams' (median wait of around 6.5 months) (Children's Commissioner, 2024).
- Autistic young people report feeling that their mental health problems result from the way autistic people are pressured to act in a neurotypical world. They state they face many barriers and delays to accessing mental health interventions, as well as facing stigma around both mental illnesses and autism; with one survey finding that 68% were not confidence that they could get appropriate support for their mental health needs (Crane, Adams, et al., 2019).
- There is some evidence suggesting that autistic children and children with other neurodevelopmental conditions are more likely to be absent from school and experience 'school distress' (Connolly et al., 2022; Department for Education, 2022).

It is important to consider the needs of the families/carers of autistic children and children with ADHD, a proportion of whom may also be autistic and/or have ADHD. Parents/carers can experience stigma and stress, and have their own mental health needs, with research suggesting this correlates with the autistic person's mental health (Lai, 2023).

Primary care

- General practitioners play a key role in identifying autism, providing mental health interventions and referring autistic children and young people to other services (Coughlan et al., 2020). Literature suggests that parents/carers are likely to go to their family GP as a first point of contact with questions around their child's development or behaviour, with this 'pre-diagnostic period' often being a stressful time for families (Coughlan et al., 2020).
- Autistic children and young people are likely to present to general practice with more complex needs, including psychological and social issues, than their non-autistic peers (Foley et al., 2018). Similarly, one recent study found that children with ADHD were twice as likely to attend their GP as those without (Prasad et al., 2024).

Children and young people's mental health services (CYMPHS)/YOUnited

- Neurodevelopmental conditions were the third most common referral reason to children and young people's mental health services in England in 2022-23 (Children's Commissioner, 2024).
- Similarly, in Cambridgeshire and Peterborough, support around autism and/or ADHD was one of the top 5 reasons people are referred to YOUnited in July 2023. This may be to access diagnostic assessments, ADHD medication, or to receive mental health interventions.

Crisis services

International research suggests that young autistic people and people with ADHD may be at higher risk of experiencing a mental health crisis:

- One international study found that children with an autism diagnosis were 9 times more likely to attend Accident and Emergency due to their mental health, compared to children without an autism diagnosis (Kalb et al., 2012).
- Another international study found that over 1 in 4 young people attending Accident and Emergency due to their mental health had a diagnosis of ADHD and/or autism (Bourke et al., 2021).

Inpatient

- The NHS Long Term plan set a target that, by March 2023, the rate of children and young people with autism and/or a learning disability being cared for in an inpatient mental health unit would have decreased to half the rate in 2015 (to between 12 to 15 children, per one million children) (NHS, 2019).
- Research involving autistic children and young people with experience of CAMHS inpatient services highlights that the sensory experiences of inpatient wards can be overwhelming and harmful for autistic people, can prevent them from being able to engage in interventions and can contribute to long hospital stays (NDTi, 2020).
- Support which is specifically designed for autistic young people may help to improve outcomes in inpatient settings. For example, staff training and the use autism-specific interventions in one mental health unit was associated with a 40% decrease in length of hospital stay and 77% decrease in the use of holds and restraints (Kuriakose et al., 2018); with some of these outcomes being sustained in the 18 months after this pathway was introduced (Cervantes et al., 2019)

There is no national guidance specifically around the needs of young people with ADHD in inpatient mental health settings, and limited research about this group.

Transitions between child and adult services

Young adulthood is an important period of change and can be the point at which people first begin to experience the symptoms of mental ill-health (Kessler et al., 2007). Autistic people may face additional challenges in the transition to adulthood, such as being more likely to experience bullying and less likely to enter post-secondary education and employment (Crane, Adams, et al., 2019). Similarly, there is evidence that young adults with ADHD are more likely to face difficulties at school and experience more unstable employment (Kuriyan et al., 2013).

Transitions between children's and adults' mental health services have been highlighted as an issue for many young adults, at both a national and local level. National research shows that young adults with neurodevelopmental conditions are less likely to transfer into adult mental health services from child mental health services than their peers; and that there can be condition-specific barriers to service transitions, such as poor understanding of ADHD as a long-term condition (Ford, 2020).

A national survey of 315 young people with ADHD found that just 6% had an optimal transition between child and adult services (Eke et al., 2020). A review of the experiences of healthcare transitions for young people with ADHD found that (Price et al., 2019):

- Many young adults with ADHD described needing to overcome 'hurdles' to transition from child and adult services, including a lack of information and transition planning, high thresholds for adult health services and a lack of understanding about ADHD.
- Traits of ADHD can make self-organisation and managing change challenging, which can exacerbate the difficulties of navigating healthcare transitions.
- Being unable to access treatment and support at this age often had negative impacts on young people.

Likewise, national research involving autistic young adults highlights poor experiences of transition between child and adult mental health services, and concerns around less structured support in adult services (Cheak-Zamora and Teti, 2015; Crane, Adams, et al., 2019). One survey from 2019 found that only 1 in 4 autistic young adults who transitioned from children's to adults' services felt they properly supported in this process (APPGA, 2019).

Additional Resources

- "It's Not Rocket Science": Considering and meeting the sensory needs of autistic children and young people in CAMHS inpatient services
- Know Your Normal: resources for autistic young people to work out and understand what their normal is
- Supporting autistic children and young people through crisis

Working-age adults

- The earlier chapter of the mental health needs assessment covers the mental health needs of working-age adults in Cambridgeshire and Peterborough.
- Many autistic adults experience poor mental health and seek out mental healthcare, with one 2019 survey finding that over three quarters of autistic adults in England had reached out for mental health support in the preceding 5 years (APPGA, 2019).
- National research suggests that adults with ADHD often 'struggle to access appropriate healthcare', due to a lack of provision of evidence-based treatment options and limited information about services (Price et al., 2020).

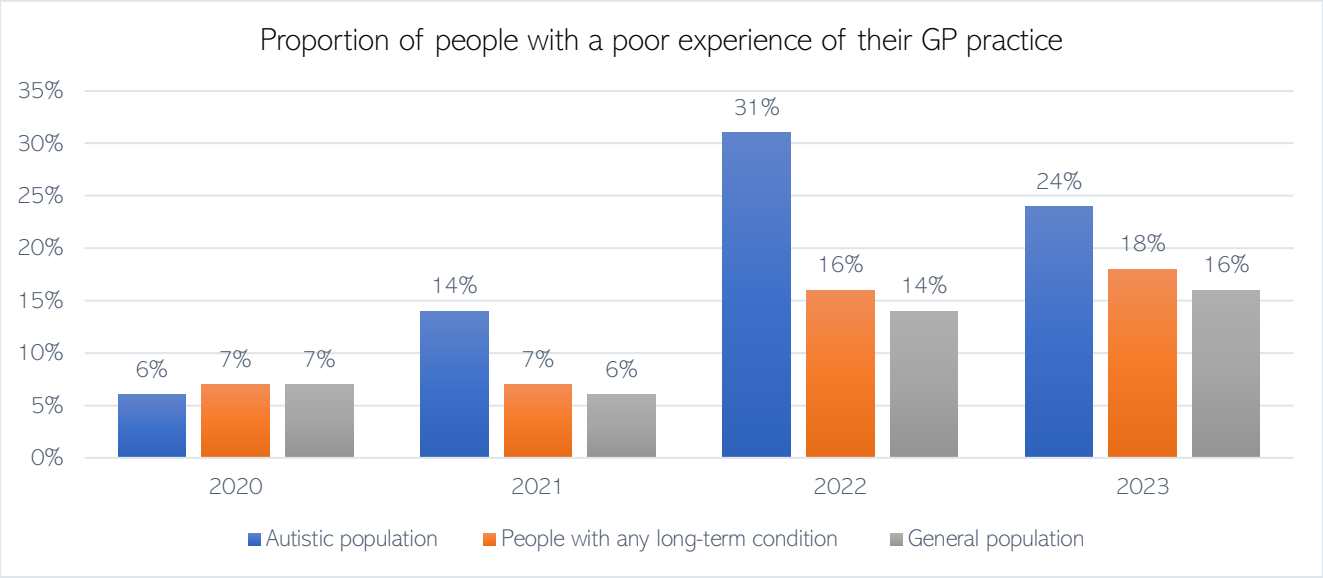
Primary care

National research suggests that both autistic people and people with ADHD can face barriers to accessing support from GPs. For example, an international review identified a range of barriers to effective support for people with ADHD in primary care, including a lack of understanding around ADHD, limited time and resources and issues in integrated pathways (French, Sayal and Daley, 2019). A national survey found that 8 in 10 autistic adults found it difficult to access their GP when needed, compared to 37% of non-autistic respondents; and that experiencing these barriers were associated with adverse health outcomes, including untreated mental health conditions (Doherty et al., 2022). The most common barriers reported by autistic people included:

- Difficulty deciding if symptoms warrant a GP visit (72% autistic respondents v. 65% non-autistic)
- Difficulty phoning to book an appointment (62% autistic respondents v. 16% non-autistic)
- Not feeling understood (56% autistic respondents v. 13% non-autistic)

Results from the GP Patient Survey suggests that autistic people in Cambridgeshire and Peterborough may have had a poorer experience of their GP between 2021 and 2023, compared to both the general population and people with long-term health conditions. Further work is needed to validate these trends, as this analysis was based on relatively small population samples.

Figure 41: Weighted proportion of respondents who answered 'poor' to the question 'overall, how would you describe your experience of your GP practice?', Cambridgeshire and Peterborough ICS, 2020 – 2023. Data source: GP Patient Survey



Note: 'poor' includes responses where people answered that their experience was 'fairly poor' or 'very poor'. The weighted base for each of these groups was:

- *Autistic population: 2020 (110), 2021 (97), 2022 (149), 2023 (179)*
- *Population with any long-term condition: 2020 (5,837), 2021 (6,766), 2022 (6,031), 2023 (6,379)*
- *General population: 2020 (11,813), 2021 (13,885), 2022 (11,738), 2023 (12,371)*

Talking Therapies

- National research shows that autistic adults are underrepresented in Talking Therapies and have poorer outcomes when accessing this service (NAS, 2021). Adults with a recorded autism diagnosis are more likely to experience worsened depression and anxiety symptoms after Talking Therapies treatment, compared to their non-autistic peers (El Baou et al., 2023).
- There is limited research into the access, experience and outcomes of Talking Therapies for people with ADHD.

Community mental health services

Guidance from the Royal College of Psychiatrists states that staff in community mental health services should be aware of the core features of autism and ADHD, and the potential for a missed diagnosis (Royal College of Psychiatrists, 2020b; Royal College of Psychiatrists in Scotland, 2023).

Example: Support for autistic people and people with ADHD within CAMEO

CAMEO (Cambridgeshire and Peterborough Assessing, Managing and Enhancing Outcomes) provides support for people aged between 14 and 65 who are experiencing their first episode of psychosis or those at risk of developing psychosis. This service provides a specialist offer of support for autistic people and people with ADHD, including the provision of autism/ADHD diagnostic assessments within CAMEO, adjustments to how interventions are delivered and awareness across all staff of how autism or ADHD traits may impact how psychosis presents.

In 2019, 3 staff members were trained to deliver autism and ADHD diagnostic assessments, and ADHD treatment, within CAMEO. These staff have shared their learning across their teams, leading to a culture shift in which, when people are referred to CAMEO, staff consider 'could autism and/or ADHD help explain this?'. Different approaches have been introduced to tailor support to autistic patients, who make up 13% of the CAMEO caseload (Treise et al., 2021). Depending on the individual, this may include:

- A focus on stressors present alongside psychosis symptoms (e.g. sensory or interpersonal issues)

- Practical interventions to target stressors and improve functioning (e.g. considering adaptations in the workplace, structured social groups to help people build social networks)
- Using a different approach to CBT for people with 'black and white' thinking.
- Supporting people with alexithymia to improve their introspection.

This new protocol was introduced in recognition that there was a substantial proportion of people within CAMEO who had a different clinical presentation and for whom the typical interventions did not meet their needs – such as people whose symptoms did not improve after receiving cognitive behavioural therapy (CBT), or who had unusual reactions to medication (Treise et al., 2021).

Eating disorder services

- A high proportion of people receiving treatment for eating disorders are autistic, with research estimating that over 1 in 5 people with eating disorders are autistic (Huke et al., 2013). There is also evidence suggesting that eating disorders may be more common among people with ADHD, particularly bulimia and binge eating disorder (Nazar et al., 2014).
- Research involving autistic women emphasises that their specific needs are not always met in eating disorder services, in part due to a lack of staff understanding of autism (Babb et al., 2021). The PEACE pathway is the only intervention aimed at autistic patients with eating disorders described in literature, (Li et al., 2022).

Crisis services

The NHS Quality Improvement programme Getting It Right First Time (GIRFT) states that 'providing the right treatment at the right time' reduces the chance that people reach the point of mental health crisis (Davidson, 2021).

There is limited research looking into access or experience of crisis services by autistic people and people with ADHD (Balazs and Kereszteny, 2017; Cassidy et al., 2018). One American study found that autistic adults were 2.6 times more likely to attend Accident and Emergency because of their mental health than non-autistic adults (Vohra, Madhavan and Sambamoorthi, 2016); however, a recent review did not identify any studies looking into autistic people's access to or experience of mental health crisis lines (Cleary et al., 2022).

Locally, Cambridgeshire, Peterborough and South Lincolnshire Mind (CPSL Mind) have been awarded grant funding from the Department of Health and Social Care Suicide Prevention Fund. This project aims to take existing Stop Suicide Campaign and workshops and tailor training and resources for 3 high-risk communities:

- LGBTQ+
- Neurodivergent
- Migrated

CPSL Mind have partnered with The Kite Trust, Safe Soulmates and The Boston Wellbeing Hub respectively to coproduce and tailor the new workshops. In Summer 2024, they will offer bespoke workshops to staff and volunteers of organisations who work alongside these three high risk communities.

Additional Resources

- Care and support for autistic adults in Cambridgeshire
- Royal College of General Practitioners adult autism and ADHD toolkit
- Autism Spectrum Disorder in Early Intervention in Psychosis Services: Implementation and Findings of a 3-step Screening and Diagnostic Protocol
- Good practice guide: For professionals delivering talking therapies for autistic adults and children
- PEACE (Pathway for Eating disorders and Autism developed from Clinical Experience)
- Tips to help support neurodivergent people

Inpatient

An overview of inpatient mental health services is included in a previous section of the mental health needs assessment.

- The National Autistic Society states that 'it is widely recognised that for most autistic people, care in an inpatient unit is rarely helpful—in fact, it can be deeply damaging' (NAS, 2023).
- 16% of autistic adults in mental health inpatient settings received a formal autism diagnosis after being admitted into inpatient care (NHS England, 2023d).
- There has been a range of national policies and targets in recent years that have aimed to improve inpatient mental health settings for autistic people, including a renewed focus on reducing admissions of autistic people to inpatient care and increasing discharge rates (NHS England, 2024).
- CPFT is currently part of the national learning disability and autism inpatient quality transformation programme. The programme is built upon the cornerstones of good mental healthcare; continuity of care, therapeutic relationships and a commitment to mental health care meeting the needs of all citizens.

The information below focuses on the experiences and outcomes of autistic people in inpatient mental health settings. Despite the high rate of undiagnosed ADHD in inpatient mental health settings, there is little research into tailored support and treatment for this group (Lines and Sadek, 2018).

Rates of inpatient admissions

- The NHS Long Term set the goal that, by March 2023, the number of autistic people in inpatient mental health settings would fall to half of 2015 levels (NHS, 2019). However, the number of autistic inpatients in England increased from 2015 to 2024 (Abreu, Parkin and Foster, 2024).
- The Care Quality Commission's report '*Out of sight – who cares?'* found that autistic people who did not get the care and support they needed in the community, such as due to long waiting lists for an autism assessment or a lack of specialist support services, can end up experiencing a 'crisis point' in which the 'only option' is mental health inpatient services (CQC, 2020).
- The introduction of the Dynamic Support Register (DSR) and Care (Education) and Treatment Review (C(E)TR) policy aims to prevent unnecessary hospital admissions for autistic people and people with a learning disability (NHS England, 2023b).

Length of stay

National data shows that some autistic people spend long periods of time in inpatient mental health settings. In October 2023, half of people with a learning disability and/or autism in hospitals in England had been in hospital for over 2 years (Tudor, 2023).

Experience

The Care Quality Commission's report '*Out of sight – who cares?'* highlights that spending time on noisy and chaotic hospital wards can heighten autistic people's distress. Some autistic people may express this distress in ways that other people find challenging; and in some cases this behaviour can be 'managed' through restraint, seclusion and segregation, rather than by addressing the underlying cause (CQC, 2020).

National research involving people with learning disabilities and autistic people (including autistic people with learning disabilities) in long-stay hospital settings, as well as family members, commissioners and healthcare professionals, found that (Glasby et al., 2024):

- People in hospital often feel frustrated and that hospital environments are not environment that is conducive to them getting better or staying well, and that they face multiple barriers to leaving hospital.
- Frontline staff feel they are working a complex system that is extremely difficult to navigate.
- There is not a shared sense of how many people need to be in hospital or could be cared for in different settings across hospital staff.

Additional Resources

- Acute inpatient mental health care for adults and older adults
- The Discharge Toolkit
- My heart breaks - solitary confinement in hospital has no therapeutic benefit for people with a learning disability and autistic people

Older adults

There is limited research looking at the mental or physical health needs of autistic older adults or older adults with ADHD, despite health needs often increasing with age (Torgersen et al., 2016; Ward, 2019).

- Some international studies suggest that older adults with ADHD are more likely to experience anxiety and depression than their peers, which may be linked to adverse life events (Torgersen et al., 2016). There is also some research suggesting that ADHD may be a risk factor for dementia (Becker et al., 2023).
- Some have suggested that there may be a 'silent crisis' among autistic older adults, due to relatively high rates of depression and suicide, with limited support for people in this age group (Robison, 2019). One small study found a high prevalence of mental health conditions among older autistic adults (Bishop-Fitzpatrick and Rubenstein, 2019).

Recommendations for future work

Local population

- Continue to capture the lived experience of autistic people and people with ADHD, including a focus on the experiences of people from a range of ethnic backgrounds and people in contact with the criminal justice system.
- Improving system understanding around neurodiversity and make sure that strategies recognise that many autistic people and people with ADHD have other neurodevelopmental conditions, as well as mental health needs.
- Ensure future strategies and planning around mental health services recognise that autistic people and people with ADHD are more likely to experience mental health conditions.
- Ensure future strategies and planning around physical health services recognise that autistic people and people with ADHD are more likely to experience some physical health conditions.

Wider determinants and inequalities

- Investigate support for people with ADHD and autistic people at risk of homelessness, and those experiencing homelessness, in Cambridgeshire and Peterborough
- Investigate access to ADHD and autism assessments and support for people in contact with the criminal justice system, including people in prison and leaving prison, to ensure that continuity of care and medication is a priority for these populations.
- Strengthen partnership working between Early Help and social care services, with autism and ADHD services.
- Recognise that autistic people and people with ADHD are an important group to consider in trauma-informed approaches and should be integral to the development of a trauma informed approach.
- Continue to investigate, and address, the barriers to healthcare faced by trans people who are autistic and/or have ADHD.

Assessment, diagnosis and management

- Develop a communication strategy for the general population about ADHD and autism services in Cambridgeshire and Peterborough. This should be accessible and recognise that many autistic people and

people with ADHD have developmental language disorders; as well as including information around the ADHD medication shortage.
- System work is needed on the commissioning of autism and ADHD assessments, relatively to the size of people in the local population and increased demand for assessments.
- Assess the offer of pre/post-diagnostic support for ADHD and autism.
- Investigate current pathways, referrals and wait times for people with multiple neurodevelopment conditions.
- Ensure that service planning for ADHD and autism assessments have a focus on equitable access for diagnosis and treatment, including age, gender, ethnicity, district, substance use, criminal justice involvement.
- Evaluate the case for offering joint assessments for autism and ADHD, when relevant.
- Align with PCREF work to understand inequalities in access to autism and ADHD assessments for children and adults from Black and Asian and other minority ethnic groups.
- Look into access to autism and ADHD assessment for young adults, including whether young people transitioning from child to adult services wait longer to access assessments.

Barriers and facilitators

Recent work done as part of the local Learning Disability Long-Term Improvement Programme identified similar issues in terms of barriers to access to mainstream mental health services faced by people with learning disability, including commissioning arrangements, workforce training and reasonable adjustments. This should be joined up with work around autism and ADHD where relevant.

- Deep dive into what are reasonable adjustments in mental health services for people with ADHD and Autism, whether diagnosed or not, and the support that services need to be able to provide these (e.g. technology, training).
- Develop an ICS-wide strategy to meet NHS England guidance around meeting the needs of autistic adults in mental health services.
- Evaluate the evidence base for early interventions that can support autistic people and people with ADHD, to support mental wellbeing and prevent mental illness. This should include different types of digital support.
- Promote the use of the NHS Digital Flag for reasonable adjustments, including awareness among staff and patients.
- Continue to investigate staff training needs, including awareness of the protocol for people with a learning disability and/or autism on Dynamic Support Registers and Care and Treatment Reviews (CTRs). Develop a plan to address training needs around autism and ADHD, so that frontline workers are able to consider if mental health needs are linked to challenges related to autism and/or ADHD.

The following recommendations are based on the survey results:

- Promote collaboration and joined up working around autism and ADHD across mental health services, primary care, social care, education, criminal justice, out of hours and crisis services.
- Investigate adjustments in online appointments in mental health services, including best practice and current provision in Cambridgeshire and Peterborough.
- Promote understanding of how best to involve and support family and friends, when their loved one is receiving care in mental health services.

Mental health interventions

- Look into patterns of rejected referrals into mental health services for autistic people and people with ADHD and use this to inform understanding of reasonable adjustments.
- Investigate access and experience of primary care for autistic people and people with ADHD.
- Further work is needed to understand the needs of older autistic adults and older adults with ADHD.
- Start to segment outcomes for people with ADHD and/or autism across mental health services.

- Ensure a digital mental health strategy considers the benefit of digital mental health tools for autistic people and people with ADHD.
- Continue to work on understanding the range of effective therapeutic interventions for people in mental health services with ADHD and autism across all ages.

Appendix

How was ADHD prevalence calculated?

Estimates for ADHD prevalence vary by age group and methodological approaches used in different studies (Posner, Polanczyk and Sonuga-Barke, 2020). For these estimates, we have used the following sources:

- Prevalence in children and young people (under 18s) was calculated Polanczyk et al.'s 2007 review.
- Prevalence in adults aged between 18 and 50 was calculated from Fayyad et al.'s 2018 screening study.
- Prevalence in adults aged 50+ was calculated from Dobrosavljevic et al.'s 2020 review.

The table below summarises information about ADHD prevalence for under 18s. It includes different data sources, estimated prevalence, and the strengths/weaknesses of these sources.

Table 12: Summary of data sources on ADHD prevalence in children and young people

Data source	Prevalence	Sex ratio	Notes
Polanczyk et al. 2007 meta-analysis	5.29% (5.0 – 5.6%)	Found that gender is significantly associated with prevalence, but there was not enough stratified data to include gender in final regression model.	Worldwide prevalence, based on 102 studies.
NICE	~5%	Guidance states that 'ADHD is more commonly diagnosed in boys than girls. Prevalence ratios are generally estimated at 2–5:1, while clinic populations show a ratio as high as 10:1'	Guidance states that differences in presentation (boys present more often with disruptive behaviour and are more likely to have conduct disorder; whilst girls are more likely to have the inattentive subtype of ADHD) may contribute to differences in diagnosis rates.
Willcutt 2012 meta-analysis	5.9 – 7.1% depending on methodology	Found that males were more likely to meet ADHD criteria than females (3.2:1 in 'best estimate' models) but that there were too few stratified studies to include sex in the final prevalence models.	Worldwide prevalence, based on 88 studies (n = 163,688). Estimates differed by methodology, including self-report (5.0%), teacher ratings (7.1%), parent ratings (6.1%), and best estimate diagnostic procedures (5.9%).
Erskine et al. 2013 modelling for GBD	2.2% boys 0.7% girls	Male: female ratio of 3.2:1 was calculated from a range of studies.	Worldwide prevalence, based on 44 studies of children aged 5 – 19 years. This study gave a more conservative estimate, as it gave a greater weight to studies in which information was required from more multiple informants and included a higher proportion of 12 – 18 year olds.
Polanczyk et al. 2015 updated meta-analysis	3.4% (2.6 – 4.5%)	Did not investigate	Worldwide prevalence, based on 33 studies (n = 77,297).

Thomas et al., 2015 meta-analysis	7.2% (6.7 – 7.8%)	Did not investigate	Worldwide prevalence, based on 175 studies. Prevalence is higher than other meta-analyses, as this analysis included as many studies as possible.
Mental health of children and young people in England survey 2017	1.6% (hyperactivity disorders)	Found a prevalence rate of 2.6% in boys and 0.6% in girls.	ICD-10 definition of hyperkinetic disorder is similar but more restrictive than the DSM-5 classification of ADHD, hence these rates are likely to be underestimates.

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