INTRODUCTION

Autism is a lifelong developmental condition that affects how people communicate and interact with the world. It is diagnosed on the basis of differences in social interaction and communication, plus unusually restricted interests and repetitive activities, and includes what was previously termed Asperger’s syndrome. Between 1% and 3% of the population are autistic. Box 1 outlines common challenges experienced by autistic people. Box 2 outlines identification and initial assessment of possible autism, and Box 3 describes accommodations that may help autistic people to access health care. Recommended approaches include offering continuity of care and getting to know the autistic patient and their own specific needs, including reasonable adjustments.

UNDERDIAGNOSIS OF AUTISM

Over the past 20 years, growing awareness and changes to diagnostic criteria have led to a rise in the prevalence of diagnosed autism and the numbers of people self-identifying as autistic. Epidemiological research suggests that there are similar numbers of autistic people across different age groups, but the rate of diagnosed autism in adults is low. Most autistic adults in England may be undiagnosed. Recent estimates suggest that three times as many males are autistic as females, though this may reflect a bias in study design.

It is often stated that around 50% of autistic people have an intellectual disability (for example, in Madsen et al). However, the true prevalence of moderate or severe intellectual disability in people who meet diagnostic criteria for autism is closer to one in ten. Autistic people who have few support needs are less likely to be diagnosed, though they may still experience substantial difficulties in their lives.

Epidemiological research published in 2011 suggested that just over 1% of people are autistic. However, the assessments used often miss autistic people who adopt strategies to minimise their social differences. Therefore, autistic people with a high IQ and autistic women were likely under-identified. Diagnostic criteria for autism have broadened since the study was conducted: in ICD-11, subgroups (for example, childhood autism and Asperger’s syndrome) have been removed in favour of an overarching ‘autism spectrum disorder’ category.

Currently, around 3% of children and young people are being diagnosed as autistic. A similar proportion of adults might meet criteria if they were assessed. Many would not be recognisably autistic to practitioners without specialist training. ICD-11 notes that many autistic people are ‘able to function adequately in many contexts through exceptional effort, such that their deficits may not be apparent to others. A diagnosis of Autism Spectrum Disorder is still appropriate in such cases’.

Many autistic women are misdiagnosed with a borderline/emotionally unstable personality disorder because of similarities in their presentation to aspects of these conditions, and misconceptions about how autistic females present. Misdiagnosis means that autistic women are misunderstood, stigmatised, and are missing out on autism-specific adaptation and the psychological benefits of knowing they are autistic.

AUTISTIC IDENTITIES

Autistic people are increasingly challenging the assumption that autism equates to a series of ‘deficits’. They dispute the concept of disorder and the need for them to be ‘fixed’, and note that developmental differences are natural variations of human minds, and that ‘people who diverge from the norm (neurominorities) are equally deserving of dignity, respect, and accommodation’.

This perspective emphasises the negative impact of the expectations of a society oriented towards non-autistic people.
that discriminates against those who do not conform. For example, honesty and directness on the part of an autistic person may be perceived by service providers as an attempt to challenge their authority, leading to exclusion of the autistic person. Many autistic people experience anxiety, confusion, stress, and distress over society’s lack of understanding; and, as a result, isolate themselves. In terms of health care, this can result in delayed presentations and a lack of help seeking. One of the best ways to support autistic people is to accommodate their differences. This includes providing excellent structure and organisation, consistency, and using simple and direct language (avoiding metaphor or sarcasm), plus accommodating sensory needs (for example, providing access to a quiet waiting environment).

**Box 2. Identification and initial assessment of possible autism (NICE)**

Consider assessment for possible autism when a person has:

- one or more of the following:
  - persistent difficulties in social interaction
  - stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, and

- one or more of the following:
  - problems in obtaining or sustaining employment or education
  - difficulties in initiating or sustaining social relationships
  - previous or current contact with mental health or learning disability services
  - a history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.

For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism Spectrum Quotient — 10 items (AQ-10). (If a person has reading difficulties, read out the AQ-10.) If a person scores 6 or above on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism.

For adults with possible autism who have a moderate or severe learning disability, consider a brief assessment to ascertain whether the following behaviours are present (if necessary using information from a family member, partner or carer):

- difficulties in reciprocal social interaction including:
  - limited interaction with others (for example, being aloof, indifferent or unusual)
  - interaction to fulfil needs only
  - interaction that is naive or one-sided
  - lack of responsiveness to others
  - little or no change in behaviour in response to different social situations
  - limited social demonstration of empathy
  - rigid routines and resistance to change
  - marked repetitive activities (for example, rocking and hand or finger flapping), especially when under stress or expressing emotion.

If two or more of the above categories of behaviour are present, offer a comprehensive assessment for autism.

**CHALLENGES EXPERIENCED BY AUTISTIC PEOPLE**

Autistic adults experience specific risk factors for premature morbidity and mortality, including social exclusion, housing insecurity, and discrimination, plus negative life events (for example, domestic abuse, victimisation, and financial exploitation). Depression and anxiety are particularly common. Loneliness and a lack of social support likely play a role. Social relationships facilitate management of and recovery from stress. With fewer opportunities to co-regulate emotions with supportive others, autistic people may struggle more in coping with daily stressors. Autistic adults are at an increased risk of suicide. Recent work that reviewed coroners’ reports and interviewed families of people who had taken their own lives found that four in ten of those who had died by suicide had ‘possible autism’, though none were diagnosed. Given that autistic people may lack social support, it is essential that services step in and offer the requisite support to those experiencing suicidal thoughts.

While any indication of risk to a person’s life must be taken seriously, it is also important to contextualise this: sometimes an autistic person’s life feels too painful to live, and their ‘escape hatch’ is knowing that there is a ‘way out’. Once the crisis has abated, these thoughts will often diminish. Offering kindness and understanding can support an autistic person to regain the hope that things can improve.

**IDENTIFICATION AND ASSESSMENT**

As of 2018, we estimate that fewer than one in ten autistic over-50s in England have been diagnosed, meaning that the specific needs of almost all older autistic people are invisible to services. Many autistic adults may be unaware that they are autistic, often precluding the possibility of diagnosis. A full autism assessment — leading to a formal diagnosis — requires comprehensive history taking by a clinician with expertise in autism, often using validated assessment tools, and, if available, information from friends and family. This may take several hours. Primary care clinicians, therefore, should not be expected to make a formal autism diagnosis, but should be able to recognise features suggestive of autism, and refer onwards for an assessment if appropriate.

Under the Autism Act, each local authority must have an adult autism diagnostic pathway. The Welsh Government has published a code of practice setting out expectations of local health bodies and local authorities about how autistic people are supported. GPs should use National Institute for Health and Care Excellence (NICE) guideline 142 to inform whether a referral is warranted. At present, waiting times of 2 years or more for an adult autism diagnostic assessment are common.

Box 2 outlines the contents of NICE guideline 142. Presently, the guideline states that ‘If a person scores 6 or above on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism’. The comprehensive assessment should be team based and multidisciplinary.

Practitioners who identify that a person could be autistic might not broach the subject because of stigma, or those who opt to raise
Box 3. Accommodations that may help autistic people to access health care

Sounds, smells, sensations, and crowded places can overwhelm autistic people:
- accommodate sensory needs, for example, offer a quiet place to wait, give the first or the last appointment of the day; and
- where possible, reduce sensory stress (for example, strong smells and bright lights).

Autistic people may experience extreme anxiety in unpredictable situations:
- offer an appointment with a familiar practitioner where possible;
- advise on expected timings;
- inform about what to expect during a screening or health check;
- say what is happening and what you expect to happen during an examination; and
- get to know the patient’s specific needs, including reasonable adjustments.

Some autistic people find it hard to use the telephone and/or to communicate during a consultation:
- offer an online or text-based appointment booking system;
- offer the opportunity to communicate the reason for the consultation in advance by email;
- slow the pace of verbal exchanges;
- allow processing time;
- use clear, unambiguous language;
- encourage non-speaking autistic people to use their alternative forms of communication (for example, typing or symbols) where possible;
- check that you and the patient have a shared understanding of the problem and the treatment plan;
- provide clear instructions or follow-up advice in writing; and
- refer to prescriptive resources (for example, https://www.nhs.uk).

Be aware that problems can present differently in autistic people, and they may have extra support needs:
- expect differences in emotional expression: ask about mood/anxiety and suicidal thoughts;
- ask about pain, rather than relying on non-verbal cues;
- distress behaviour or behaviours that challenge often result from unmet needs (for example, pain, discomfort, and anxiety); and
- some autistic people get stuck in certain thinking patterns. They may request detailed information.

Being inclusive is important.
- many autistic people have had experiences of being excluded, bullied, shamed, and devalued. They may struggle to trust new people; and
- offering accommodations signals to an autistic person that their health matters and gives them the best chance of receiving timely care.

the topic may meet with denial. In such cases, being mindful that the person might be autistic could still inform adaptations and adjustments, and may also alert the practitioner to potential unmet support needs.

As many as 100 000 people with intellectual disability in England may have undiagnosed autism.18 This may result in unmet needs (for example, unrecognised sensory sensitivities), leading to behaviour that challenges; these can sometimes lead to physical restraint and/or antipsychotic medication. Lack of recognition of the person’s triggers related to their autism can therefore have adverse consequences for their mental and physical health.

COLLECTING INFORMATION TO INFORM WHETHER A REFERRAL SHOULD BE MADE

The National Autistic Society (NAS) recommends that adults who think they may be autistic provide their GP with information on difficulties they’ve had with the following areas: 1) communication; 2) social interaction; 3) sensory difficulties; 4) friendships; 5) employment; and 6) need for routine, and how these have affected different areas of their life.

Autistic people often benefit from being given extra time to process questions and formulate a response, and having the opportunity to communicate in writing. They may prefer not to be asked too many questions in quick succession,19 so more than one consultation may be needed to gather necessary information.

When making a referral, it is important to address how receiving a diagnosis would be of benefit. Potential reasons include correcting a misdiagnosis (for example, of personality disorder); signposting the need for adjustments to facilitate access to services (for example, Improving Access to Psychological Therapies [IAPT]); enabling the individual to reasonable adjustments under the Equality Act; and facilitating access to support groups.

Reasonable adjustments can be critical in determining whether care is accessible and effective (Box 3),20 such as slowing the pace of verbal exchanges, allowing processing time, and providing follow-up advice in writing.21 When accessing primary care, autistic adults prefer an online or text-based appointment booking system; the opportunity to communicate the consultation reason in advance; being offered the first or last appointment of the day; and having a quiet place to wait.19

Some autistic people find it difficult to express concerns during a consultation. A recent study reported that half of autistic people with suicidal thoughts/behaviours attending a psychiatric hospital emergency room were missed during initial screenings, partly because they sought support for other issues such as a financial crisis, diagnostic clarification, or request for medication.22 It is therefore of utmost importance for practitioners to ask directly about mental health and suicidal thoughts.

SUPPORTING AUTISTIC PEOPLE

During a comprehensive autism assessment, the NICE guideline recommends that the following risks be assessed: 1) self-harm; 2) rapid escalation of problems; 3) harm to others; 4) self-neglect; 5) breakdown of family or residential support; and 6) exploitation or abuse by others. Advice on managing behaviour that challenges and supports mental health is available in NICE guideline 142.13 The guideline recommends referring autistic people with no/mild intellectual disability to an individual supported employment programme where this may be helpful, or applying to the Department for Work and Pensions for Access to Work support.23

Recent work has shown that some autistic adults benefit significantly from accessing
primary care talking therapies (for example, IAPT).24 Many autistic adults also benefit from information provided by NAS (https://www.autism.org.uk), which offers practical resources, including advice on financial benefits and accessing local authority support. Peer support via NAS or other charity-run support groups can be key to alleviating social isolation, though for some autistic people the notion of joining a group can feel overwhelming.

For autistic adults living independently, having a diagnosis may not appear to change much. Yet many people who receive a late-life diagnosis describe it as life changing, allowing them to re-evaluate their past experiences. Post-diagnostic support is important as it provides an opportunity for a newly diagnosed autistic person to review their life through an autism lens. This often leads to the realisation that they were not to blame for difficult experiences.

**CONCLUSION**

Primary care clinicians should be aware of the substantial rate of underdiagnosis of autism in adults. Successfully identifying undiagnosed or misdiagnosed autism can be life changing. Supporting autistic people to access primary care can, likewise, transform their health. While primary care professionals can make a huge difference by recognising and referring people with suspected autism, and displaying empathetic understanding and acceptance, further work is needed at a commissioning level to ensure that diagnostic autism assessments in secondary care are accessible in a reasonable timeframe.

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**Funding**

The work was supported by a grant from the Dunhill Medical Trust (reference: RP1910191). Douglas GJ McKechnie was supported by the National Institute for Health and Care Research (NIHR) as an In-Practice Fellow (reference: NIHR01988). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care. The study sponsors took no role in the design of the study, the analysis of results, or the preparation of the manuscript.

**Provenance**

Freely submitted, externally peer reviewed.

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**Acknowledgements**

We are grateful to the members of the Experts by Experience Steering Group, and other autistic people with whom we have discussed our work, for sharing their experiences with us and offering helpful feedback.

DOI: https://doi.org/10.3399/bjgp23X735525