

RCGP Position Statement on Autistic Spectrum Disorders

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Introduction

This clinical priority is about understanding autism. The role of the college is to facilitate that understanding for primary care. This includes:

- The awareness of autism as a possible diagnosis in both children and adults.
- The awareness of the reasonable adjustments that may be needed to allow equitable access to healthcare for individuals on the autistic spectrum.
- The awareness that consultation skills for those with autism are different
- The awareness that physical and mental health problems may present very differently in an autistic patient compared to a neuro-typical patient.

Overview

Autism is a lifelong neurodevelopmental disorder that affects at least 1% of the population. Over 50% of those affected do not have intellectual impairment.

The Autism Act 2009¹ was the first disability specific act of parliament in the UK. It has led to the National Autism Strategy² and three NICE guidelines (CG128, CG142 and CG170)^{3,4,5} along with NICE quality standards QS51⁶.

The re-launch of the strategy in 2014 – ‘Think Autism’⁷ – was followed by statutory guidance for health and social care staff⁸. This places a duty on Local Authorities, NHS bodies (including Clinical Commissioning groups - CCG’s) and NHS foundation trusts to ensure that autism awareness training is included within general equality and diversity training for all staff and to ensure that there is a comprehensive range of local autism training for those staff likely to have contact with adults with autism.

The economic impact of autism on the UK economy has been estimated at £32b per year and a lot of this represents lost opportunity to enable more independent life and avoid

inappropriate care costs due to unrecognized need. Autism is the single most costly medical condition in the UK, costing more than cancer, cardiovascular disease or strokes⁹.

Individuals on the autistic spectrum are often marginalized by society; they are vulnerable people who often receive poor-quality care. Their needs and those of their family and carers may well not be recognized. A recent paper from Scandinavia¹⁰ demonstrated an increase in premature mortality for almost all modalities in Autistic Spectrum Disorder.

Training and education about autism is at best patchy and often missing entirely. Our patients on the autistic spectrum do not easily fit into the usual models of care. Those without an intellectual disability do not meet the criteria for secondary care mental health services unless they have additional mental health needs, and even then will only have an “episode” of care. They may avoid health promotion activity and find specialist services distressing because of their inflexibility. They may have problems accessing our services and their families and carers are at times under intense stress dealing with the demands of everyday life. They may also present with behavior that challenges others and can use a lot of unnecessary resources because reasonable adjustments are not made to help them use the NHS effectively^{11,12,13,14,15,16}. They are particularly at risk of falling through gaps in health care provision when at the transition from children and young peoples services to adult services. For many on the autistic spectrum general practice is their only source of medical support and, importantly the only source of support for the whole family, the GP needs to be able to signpost them to other services, for example psychology services or social services.

What role should the RCGP play?

The RCGP has an important role in ensuring that those on the autistic spectrum have equitable access to health care. It should lend its support to all the public policy and legislation that already exists for this group of patients. It should ensure that the needs of those on the Autistic Spectrum are considered in all future clinical priorities.

Specifically the college can:

- **Raise the understanding of autism and promote timely diagnosis** – through education and training:
 - Increase the amount of autism in the GP training curriculum.
 - Create a web resource to promote and link to reliable sources of information.
 - Offer training through the faculties of the college.
 - Complete a review and update the RCGP e-learning module on autism.
 - Ensure autism has a place in the continuing professional development of established GPs¹⁷
- **Improve access to health care by promoting reasonable adjustments and encouraging autism awareness training** – reception staff are often the key to this:
 - Encourage clinicians to take ‘Connect to Autism training’ back to their practices.
 - Have a guide on the website ‘Making the most of your visit to the GP’ and promote this through the voluntary sector.

- Promote the ‘Top Tips for clinicians consulting with those on the autism spectrum’^{11,13,14,15,16}
Encourage primary care to take part in evidence-based research. The NICE guidelines were woefully short of evidence. Promote autism as a worthy subject for future research in primary care.
- **Work in partnership with other health bodies to improve access to appropriate healthcare.** Use all opportunities when working with other medical colleges, the Royal Pharmaceutical Society and allied health professional to raise evidence based knowledge about autism and the difficulties in accessing healthcare.
- **Support the Commissioning bodies and NHS in England, Scotland, Wales and Northern Ireland to implement National Guidelines and strategy (e.g. in England, The Autism Strategy recently refreshed as ‘Think Autism’) by promoting best practice.** Identify the people and organisations that can influence the autism agenda and lobby for greater prominence for autism. Consult on NICE indicators and QoF indicators as appropriate. Comment on commissioning guidance as it is produced. Attend the National Autism Programme Board.
- **Support the Commissioning bodies and NHS in England to implement the ‘Commitment to Carers’ guidelines and, in particular, to have regard to ‘Commissioning for Carers; Principles and resources to support effective commissioning for adult and young carers’ (December 2014)¹⁸.** This is particularly important for carers of those with autism.

What is the role of the Commissioning Bodies?

There are three areas of responsibility for Clinical commissioning groups:

- **Promote and offer Autism awareness training to all community based staff.** This training should be co-delivered with people who have autism as required by the Autism Strategy ‘Think Autism’ and the subsequent statutory guidance^{7,8}. There is a statutory duty for health and social care organizations to make autism awareness training available. CCGs should:
 - offer training in a variety of ways – with courses and e-learning opportunities.
 - ensure that all staff are aware of the importance of this training and the need to refresh the training regularly.
 - ensure that all local courses on equality and diversity include autism.
 - encourage the development of autism friendly community services in all the areas they’re responsible for, including dentistry, pharmacy and opticians.
- **Develop and publicise the local diagnostic pathways and commission appropriate autism services.** The commissioning bodies should work with families and carers to identify gaps in services and ensure people with autism can access good support in their community. NICE guidelines are clear that staff in primary care should have access to well defined local diagnostic pathways and post-diagnostic support services. They should recognize the principle that investing in care and support for the individual with autism, their family and carers at an early stage, and before a crises leads to inappropriate placements (such as Winterbourne View), and¹⁹ has the potential to transform lives and save money in the long run.

- **Work with their local autism strategy or partnership board.** There should be funded primary care involvement on the board and the commissioning bodies must contribute to the National Autism Board self assessment framework in England which is reviewed regularly

What is the role for GPs in the care and support of those on the autistic spectrum, their families and carers?

GPs are at the forefront of providing healthcare for those on the Autistic Spectrum. They are the gatekeepers to diagnostic services and the source of over 90% of other healthcare to the entire population. GPs will be aware that:

- Their staff should have access to autism awareness training and the reasonable adjustments required to ensure equitable access should have been highlighted on the records, and adhering to the Accessible Information Standard.
- Autism can present at any age as there are many individuals in whom the diagnosis has not yet been recognized. GPs should feel confident that they will consider the diagnosis and can refer to the local diagnostic pathway
- Consultation skills may need to be adapted to meet the needs of the patient– the training we receive can inadvertently disadvantage those on the autism spectrum by offering open-ended questions and too much choice ^{11,13,14,15}
Presentation of illness may be different – co-morbidity is common but the verbal skills or understanding to explain what is wrong may be limited and may present as a change in behavior. It is wrong to assume this is always due to the autism ^{3,4,5,12,16}
- Family and carers of those with autism have considerable stress and pressure in their role and may need additional support from the GP. The GP has a particularly important role in working with the whole family and signposting family and carers to other sources of information and support ^{19,20}
- The GP can make a real difference as an advocate for patients with ASD who are disadvantaged across every aspect of society including work, transport, education and social care support

Summary

The Royal College of General Practitioners has:

- Recognized Autistic Spectrum Disorder as a clinical priority and
- Is committed to promoting evidence based training in autism for all members of the primary healthcare team.
- Is committed to promoting and signposting resources that create equitable access to healthcare for our patients with autism.
- Recognizes that the family and carers of those with autism have additional healthcare needs that the GP may be in a position to support.
- Will continue to work with the National Autism Programme Board and other medical colleges to promote the autism agenda.
- Recognises that in order to make improvements in the delivery and equity of care for those people affected by autism the RCGP needs to continue its work on the staffing and workload pressures currently facing general practice.
- The RCGP is committed to this massive challenge.

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