

GPs need more guidance and training

While GPs are set to be rewarded for the quality of service they offer under the terms of their proposed new contract, this report demonstrates that people with autism spectrum disorders and their families are still missing out on effective primary care. GPs have told us that the numbers of patients with autism on their lists are increasing, but many feel that referral processes are poor and that they lack the skills and expertise to pick up the possible indicators that a patient may have an autism spectrum disorder.

In November 2002 The National Autistic Society (NAS) received 448 responses from GPs across the UK to an eight-question survey about their experience of autism. This represents a sample of approximately 1.2% of all GP partners.

The responses broke down by region as follows:

Central England	147
London / South East	69
Northern England	57
Northern Ireland	22
Scotland	63
Southern England	69
Wales	21

For most families affected by autism, GPs are a key entry point to specialist health services, which in turn can provide the diagnosis that will lead to specialist services offered by education and social services. GPs should

play a key signposting role in autism assessment and diagnosis, but must also be able to offer effective primary care to children and adults with autism spectrum disorders. For example, many children with autism experience severe constipation and chronic bowel disorders, which are often wrongly dismissed by GPs and other medical professionals as untreatable. Physical examinations may be problematic as people with autism may have altered sensitivity to stimuli such as pain, smell, noise, touch or bright lights. GPs need to use factual language, avoid abstract terms and support verbal information with visual information with these patients.

GPs may need to refer a patient with an autism spectrum disorder to specialists in diet, dental health, sleep, challenging behaviour or physiotherapy.

For adults with autism spectrum disorders, GPs need to be aware of the mental health difficulties they may experience and how these may be overcome. Still more problematic for GPs will be referring adults with suspected autism to specialists for diagnosis, as little expertise in this area exists across the country.¹

Findings

82% of GPs told us that they have seen a patient with a confirmed or suspected autism spectrum disorder in the past 12 months.

This reinforces the need for doctors to know how to treat these patients, and how to refer them on to receive specialist secondary and tertiary services. As the official MRC prevalence estimate for autism spectrum disorders is 1 in 166 for children under 8, it also suggests that a minority of GPs cannot recognise autism amongst the patients in their care.² With an average list size of 2000 patients, each GP could expect to have 18 patients on the autistic spectrum.³

Four in ten (42%) GPs told us that they did not have sufficient information to make an informed assessment about the likelihood of a patient having an autism spectrum disorder.⁴ Only 36% were confident that they did have sufficient information. This finding suggests that GPs are not communicating

effectively with other primary care professionals with greater levels of autism expertise, such as health visitors who may be trained in the CHAT checklist.⁵ As GPs are the gatekeepers to specialist autism assessment and support services are still dependent on a formal diagnosis, this is cause for extreme concern. Even more worrying is the fact that nearly three-quarters (74%) of GPs who claimed not to have seen a patient with autism in the last 12 months did not feel able to make an informed initial assessment: patients with autism who are registered with these GPs are unlikely to be proactively identified. This was highlighted as a key area for improvement in the Public Health Institute of Scotland report on autism, which described a situation where GPs 'lack the confidence or experience to identify signs that suggest prompt referral is appropriate'.⁶

The availability of information for GPs on local support services appears patchy at best. **Four in ten (41%) of GPs were not aware of sources of local support and information.** This would prevent them providing effective non-medical support to families affected by autism on their lists.

When asked about referral pathways, **more than one in eight GPs (13%) stated that they would not know how and where to refer a patient with a suspected autism spectrum disorder.**

Over a third (36%) did not believe that the referral process for autism in their area operated smoothly and efficiently. In many cases, dissatisfaction with the referral process was clearly related to a GP's own expertise in autism. **The vast majority of GPs (89%) who did not know how or where to refer a patient with suspected autism also felt that the referral process in their area was generally poor.**

Comments from GPs on the referral process included:

'The process operates smoothly but may take far too long and is diagnostic only.'
(GP – Scotland)

'Theoretically it is not too bad – in practice there are real problems and delays, lack of staff/specialists etc.'
(GP – Norfolk)

Difficulties in the referral process are clearly contributing to unacceptable delays in diagnosis for autism. **Only a quarter (26%) of GPs felt that a final diagnosis of an autism spectrum disorder was likely to be forthcoming within six months,** the timeframe identified in the forthcoming National Autism Plan for Children.⁷ By contrast, **a third (33%) felt that the diagnostic process was likely to take over a year to complete.** With the majority of interventions offered by health, education

and social services still dependent on an accepted diagnosis, this means that people with autism will continue to miss out on crucial interventions that may have an impact on their ability to live independently.

Overall, the majority of GPs feel that they are dealing with more patients with autism spectrum disorders than ever before. **Two-thirds (66%) stated that the number of patients with an autism spectrum disorder on their lists has increased in the past five years.** Only one GP stated that the number had fallen. The most significant reason for this increase was generally felt to be better awareness of the condition (83%), with a minority highlighting a real increase in prevalence, changed environmental factors or improved diagnostic practices as the key cause of the change.

This survey shows that, while autism must now be a major part of any GP's caseload, many GPs are as yet ill-equipped both to recognise the diagnostic signals for autism and to provide effective treatment for patients with an autism spectrum disorder. The responsibilities GPs face are being recognised with the proposed new GP contract, which seeks to tie greater rewards to the quality of services GPs deliver. Now is the time to for national and local agencies to collaborate to ensure that people with autism and their families are not excluded from improved primary care services.

Recommendations

- Department of Health/Scottish Executive/Welsh Assembly Government to sponsor guidance for GPs and other primary care professionals in working with people with autism spectrum disorders, based on the *Once a Day* model for learning disability.⁸
- Royal College of General Practitioners to ensure that autism awareness training becomes a mandatory part of GP continuing professional development
- Autism awareness training to be integrated into the curriculum for student doctors
- Primary Care Trusts to ensure that all primary care professionals are trained in autism awareness and understand the role that they are expected to play in the diagnostic process
- Primary Care Trusts to develop better mechanisms for informing GPs of local referral pathways for autism
- Primary Care Trusts to provide information on family support services and other services in each GP's locality, so GPs can pass this information on to families on their lists

The Royal College of GPs in conjunction with The National Autistic Society is holding a seminar on the implications for GPs and their practices for patients with autism spectrum disorders (ASD) at the Royal College on Tuesday 30 September 2003.

GPs will acquire an overview of:

- autism spectrum disorders (autism, Asperger syndrome and associated conditions)
key diagnostic points
differential diagnosis
- treatment of acquired illnesses e.g. depression
- lifetime healthcare of patients with an ASD
health checks
access to Healthcare

PGEA accreditation applied for.

**For further information please contact:
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1 See A. Powell, *Taking Responsibility: Good Practice Guidelines for Services – Adults with Asperger Syndrome*. NAS: London, 2002, p40 for more recommendations to health professionals working with a adults on the autism spectrum.
2 Medical Research Council, *Review of Autism: Epidemiology and Causes*, MRC: London, 2001
3 Based on NAS estimates for the total UK prevalence rate of people with autism spectrum disorders at 91 per 10,000.
4 This finding supports previous NAS research on diagnosis and assessment: A. Stirling & A. Prior, *Opening the Door*. NAS: London, 1999
5 CHAT (Checklist for Autism in Toddlers) – the most commonly used tool to determine whether a young child may have a developmental disorder. See S. Baron-Cohen et al. 'The early identification of autism: the Checklist for Autism in Toddlers (CHAT)', *Journal of the Royal Society of Medicine*, 93, 2000, p521-525.
6 Public Health Institute Scotland, *Autistic Spectrum Disorders: Needs Assessment Report* PHIS: Glasgow, 2001, p44
7 The NIASA report, available shortly on the NAS website: www.nas.org.uk
8 M. Lindsey & O. Russell, *Once a day one or more people with learning disabilities are likely to be in contact with your primary care team: how can you help them?* NHS Executive, 1999

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