



briefing

June 2010 Issue 202

Improving services for adults with autism

Key points

- One in 100 people are on the autism spectrum.
- Successive reports have highlighted that adults with autism are often not able to access services they need.
- The National Audit Office has found significant savings could be made by investing in services for adults with autism.
- The issue has attracted cross-party attention, with the 2009 Autism Act and the previous Government's three year strategy.
- Statutory guidance is due in December 2010 placing legal duties on local authorities, NHS bodies and foundation trusts.

The issue of service provision for people with autism has gained a considerable amount of cross-party attention over the past few years. The previous Government published its strategy for adults with autism in England, *Fulfilling and rewarding lives*, on 3 March 2010, and its first year delivery plan on 2 April 2010. The 2009 Autism Act placed a statutory requirement on the Government to publish guidance by December 2010, which is expected to be consulted on this summer. Both Wales and Northern Ireland are implementing their own strategic action plans on services and support for people with autism. The Welsh plan was published in April 2008 and the Northern Ireland plan in 2009. They cover both children and adults with autism.

This *Briefing* summarises the key points of *Fulfilling and rewarding lives* and the first year delivery plan that accompanies it, focusing particularly on what it means for the NHS.

Background

It is estimated that one in every 100 people are on the autism spectrum.¹ A significant proportion also have a learning disability, although autism is not a learning disability itself. People with autism are particularly vulnerable to mental health problems such as anxiety and depression. Adults with autism require varying levels

and types of support, ranging from 24-hour care support to some level of daily help with particular tasks, to less intensive forms of support. Adults with autism will usually come into contact with either learning disability services and/or local mental health teams. Yet because autism is a developmental disorder, not a learning disability or a mental health problem, it is

often said that many adults with autism are falling through gaps in services. The needs of adults with autism cut across traditional care service boundaries, creating provision challenges as people with the condition try to access services.

Two thirds of adults with autism report that they do not have enough support to meet their needs and 82 per cent say that with more support they would be less isolated. 67 per cent have experienced anxiety and 33 per cent have developed a serious mental health problem.²

In late 2008, Conservative MP Cheryl Gillan introduced a private member's Bill on autism to Parliament. Following negotiations with the Government, the Bill became law in November 2009. The final Act does two key things. Firstly, it puts a duty on Government to produce an autism strategy by 1 April 2010 (which the previous Government subsequently did publish in March of this year). Secondly, it places a duty on Government to produce statutory guidance for local authorities, NHS bodies and NHS foundation trusts on the provision of services for adults with autism by 31 December 2010. Consultation on that statutory guidance is due to take place over the summer of 2010. Given that there is a legislative requirement for the Government to do so and that the original Bill was introduced by a Conservative MP, despite the change in administration the timetable for this is unlikely to change significantly.

The Act states that the guidance must cover the following areas:

- provision of relevant services for diagnosing autism
- identification of the numbers of adults with autism at a local level
- assessment of the needs of adults with autism for relevant services
- transition planning
- other planning in relation to the provision of services for adults with autism
- training of staff who provide relevant services to adults with autism
- local arrangements for leadership in relation to the provision of relevant services.

Following the publication of the three year strategy, *Fulfilling and rewarding lives*, the Government published a first year delivery plan, setting out key priorities for action in year one. A delivery plan for years two and three is due to be published in December 2010. The strategy is due to be comprehensively reviewed in 2013.

It is not expected that the new Government would seek to take a different approach to policy. However, it will be for the new Government to make any decisions on what elements of the strategy and delivery plan to accept and which to revisit. The Mental Health Network will keep members informed of any changes to policy in this area.

'A recent study by researchers at King's College London estimated that autism costs the UK economy around £28.2 billion per year (£25.5 billion for adults and £2.7 billion for children)'

Implementation of the strategy is overseen by a National Programme Board, co-chaired by the Minister of State for Care Services and the Director General of Adult Social Care at the Department of Health (DH). The NHS Confederation is represented on the board. At a regional level, deputy regional directors of social care (DRDs) are tasked with overseeing implementation. From June 2010, DRDs must put in place a regional planning mechanism to develop regional implementation plans for the strategy. Planning should involve directors of adult social services, directors of children's services, strategic health authorities, other relevant partners and third sector groups, with involvement from people with autism and their carers, with delivery plans in place by January 2011 and action plans by April 2011.

The rest of this *Briefing* summarises the key points of *Fulfilling and rewarding lives* and the first year delivery plan that accompanies it, focusing particularly on what it means for the NHS.

The economic case

A recent study by researchers at King's College London estimated that autism costs the UK economy around £28.2 billion per year

What is autism?

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how an individual makes sense of the world around them. It is a spectrum condition, so different people are affected in different ways. The three main areas of difficulty are with:

- social interaction: including recognising and understanding other people’s feelings and managing their own
- social communication: including using and understanding verbal and non-verbal language
- social imagination: including the ability to understand and predict other people’s intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. Asperger syndrome is a form of autism. In this *Briefing*, the term ‘autism’ is used to refer to all conditions on the spectrum including Kanner autism, classic autism, Asperger syndrome, high functioning autism and pervasive developmental disorder (PDD).

(£25.5 billion for adults and £2.7 billion for children). Of the £25.5 billion cost for adults, 59 per cent is accounted for by services, 36 per cent through lost employment for the individual with autism, and the remainder by family expenses.³

Whilst there are high-quality examples of where services for adults with autism are established and working well, it is the case that in some areas the availability of appropriate services is poor. Adults with autism, and particularly those with high functioning autism or Asperger syndrome, often only gain contact with services when their needs become acute, and at this point they require more intensive, high-level interventions and crisis management, such as psychiatric inpatient care.

The strategy states: “As many areas have shown, there is a clear business case to be made for improving the services available for adults with autism locally, and adopting a more preventative, supportive approach. For example, several areas have been able

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to reallocate resources from inappropriate placements of adults with autism in full-time psychiatric care; instead, they are able to provide day-to-day support that is more cost-effective and typically gives adults with autism greater independence”.

Additionally, the National Audit Office (NAO) states that whilst routine data on numbers and costs of people with autism on out-of-area placements is limited, it speculates that where local services are not geared up to dealing with autism, this could contribute to use of out-of-area placements. As part of the focus on improving quality and productivity in mental health it is likely that expenditure on these sorts of placements will come

under increasing scrutiny. The NAO, in its analysis of the needs of adults with high functioning autism or Asperger syndrome in particular, whilst cautioning that further work is needed to quantify costs and benefits more precisely, found that if local services identified and supported 4 per cent of those adults the outlay needed to provide such services would become cost neutral over time to overall public expenditure. Furthermore, it found that if they did the same for 8 per cent it could save the Government £67 million per year.⁴ In Liverpool, for example, the Asperger team has an estimated identification rate of 14 per cent.

Key strategy themes

The three year strategy, *Fulfilling and rewarding lives*, identifies five key areas for action for public services to improve support for adults with autism in England:

1. increasing awareness and understanding of autism

Case study: Liverpool Asperger Team

The Liverpool Asperger Team, established in 2003, is a multi-disciplinary team for adults with Asperger syndrome and is regularly held up as an example of good practice. Funded by Liverpool PCT and the local authority, it consists of a team manager (who is also a head speech and language therapist), two community nurses, two clinical psychologists, an assistant psychologist, a social worker, two support workers, an assistant clinician and an administrator.

The team has a person-centred approach and provides assessment and diagnosis of Asperger syndrome, offers direct support through its managed care pathway approach, and makes referrals on to other services.

The team also works with local services, including schools and colleges, mental health services and specialist services, such as those for people involved in the criminal justice system and those receiving support from mental health and alcohol and substance misuse services. The team also offers training and advice to professionals about autism.

2. developing a clear, consistent pathway for diagnosis of autism
 3. improving access for adults with autism to the services and support they need to live independently within the community
 4. helping adults with autism into work
 5. enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities.
- and further development of specialist training in autism among health and social care professionals locally is key. This will support more accurate referrals for diagnosis and enable health professionals to adapt their behaviour to ensure that they are properly supporting adults with autism to access healthcare. It will also help ensure that where health professionals are supporting people with particularly complex needs, they will be able to seek guidance and support from those with expert knowledge of autism.

Increasing awareness and understanding of autism

The strategy identifies awareness raising and training in how to support people with autism as fundamental to improving services for adults with the condition.

For the NHS and health professionals, developing knowledge of the signs of autism

'For the NHS and health professionals, developing knowledge of the signs of autism and further development of specialist training in autism among health and social care professionals locally is key'

This work will include the development of online resources, including Skills for Health toolkits. The DH is working with the General Medical Council, the Postgraduate Medical Education and Training Board and the Royal Colleges to help ensure that autism is included in the core training curricula for doctors, nurses and other clinicians. It is also working with relevant social and healthcare training bodies to ensure that autism awareness training can be incorporated into new and existing training portfolios.

At a local level, whilst training should be available to everyone working in health and social care, primary care trusts (PCTs) and local authorities will want to identify priority groups for training, including those working directly with adults with autism in residential or day care or in supported living services.

Developing a pathway for diagnosis

The strategy recognises that while some local areas, often through mental health trusts, have taken the initiative and developed diagnostic and assessment services linked to support, there is a wide variation across the country in rates of identification. Without a diagnosis, adults with autism can find it difficult to access support.²

‘Two thirds of adults with autism report that they do not have enough support to meet their needs and 82 per cent say that with more support they would be less isolated’

The strategy seeks to address these issues by:

- setting out a clear expectation that by 2013 there will be a pathway to diagnosis in every local area
- recommending the local appointment of a senior professional to lead on the development of the pathway, and to develop a local diagnostic and assessment service for adults with suspected autism
- committing the National Institute of Health and Clinical Excellence (NICE) to develop guidelines on model care pathways to form the foundation of local referral and care
The guidelines are due to be published in June 2012
- NICE is also developing guidelines on diagnosing autism in children, which should help ensure that people are diagnosed at an early age. This is expected to be completed by September 2011
- setting out that a diagnosis of autism will trigger a community care assessment and a carer’s assessment
- committing to set out in statutory guidance the type of information that should be provided to adults with autism and their parents/carers once

they have been diagnosed. Diagnosis and assessment are a key area that the statutory guidance will address.

Improving access to services and support

The strategy recognises that adults with autism often face challenges in accessing the support they need. It highlights the requirements on services under the Disability Discrimination Act to make reasonable adjustments for adults with autism and stresses the importance of personalised care and support.

The strategy sets out that:

- the Standard Contract for Mental Health and Learning Disabilities for 2010/11 explicitly requires service providers to explain how reasonable adjustments for people with autism are made
- by the end of 2010, the DH will publish guidance for mental health and learning disability services on ‘reasonable adjustments’ for adults with autism
- the DH, in its plan to extend the Payment by Results for mental health programme, is to include adults with autism more effectively
- personal budgets should be made available to all adults with autism who are eligible for social care services
- local authorities should work with the third sector to support the development of advocacy and buddying schemes

- there is a range of ongoing work within the Department for Education to ensure transition planning gives people with autism the right start in adult life.

It should be noted that transitions from child and adolescent mental health services (CAMHS) to adult mental health services are likely to be looked at in more detail in the forthcoming NICE guidelines on diagnosing and managing autism in adults. Transition is also an area that will be looked at in the statutory guidance.

Helping adults into work

Only 15 per cent of adults with autism are in full-time employment.⁵ That has clear implications for individuals and their families both financially and in terms of social inclusion. It also, through the welfare system, has a significant knock-on effect in terms of costs to the public purse.

To help support adults with autism into work, the strategy sets out plans for disability employment advisors (DEAs) to have training in autism.

Moreover, new initiatives from the mental health employment plan *Work, recovery and inclusion*, such as internships and cover for episodic absences, are to be available to support adults with autism.

The strategy also highlights that actions in *Valuing employment now* are designed to meet the needs of people with autism even when they do not have a learning disability, including job coaches and Project Search pilots.

Case study: Bristol Asperger Syndrome Service

The Bristol Asperger Syndrome Service (BASS) is a multi-agency, Bristol PCT commissioned team, based within Avon and Wiltshire Mental Health Partnership NHS Trust. It was set up both to help people with Asperger syndrome access a range of appropriate mainstream services, and to develop the ability of agencies across the care network to provide genuinely inclusive, high-quality services to this client group.

They have a wide range of current initiatives around improving access, developing the competencies of health and social care staff, plus interventions designed to promote social inclusion and minimise contact with mental health services. In addition to this, the team has a particular focus on increasing access to employment and suitable housing. Links have been established with local employment agencies, and a specific training pack has been produced to help employers and agencies understand both the needs, and the strengths, of people with Asperger syndrome as employees.

Enabling local partners to develop relevant services

There are a number of key recommendations and actions in the strategy which seek to address a range of local challenges to ensure adults with autism no longer 'fall through the gaps' between services.

At a local level, the strategy and delivery plan sets out the following key recommendations:

- the appointment of a lead commissioner/manager with responsibility for autism in every local authority
- local partners to develop a local commissioning plan for services for adults with autism
- the establishment of local autism partnership boards, planning groups or similar. Examples of existing planning groups are included in the delivery plan. Membership typically includes representatives from local statutory agencies as

well as people with autism and parents/carers

- the development of a local autism team. There are a number of different examples of these teams across the country, funded either by PCTs, local authorities or jointly funded.

To support this work at a national level, the DH makes the following commitments:

- the core dataset for joint strategic needs assessments (JSNAs) will be updated so that it includes the numbers of adults with autism. This will help local authorities and PCTs to ensure they are including the needs of adults with autism when they produce the JSNA and will also support local commissioning plans
- the DH will develop a protocol on recording and sharing information between services. The protocol will also look at better data collection at a local

level. This is expected to be published in December 2010

- the commissioning of an adult autism prevalence study. The study is expected to report in 2011
- the recently launched Public Health Observatory (PHO), tasked to collect data on people with learning disabilities, will also collate information relating to adults with autism across the spectrum
- sample business cases for local partners to use to support the setting up of specialist autism teams will be published in December 2010
- a self-assessment checklist for local areas to help them assess their progress will be published in December 2010.

Mental Health Network viewpoint

Through the 2009 Autism Act, and subsequent Government strategy *Fulfilling and rewarding lives*, we can see a clear national picture of how autism services are expected to develop over the coming years.

This summer we expect to see publication of a consultation ahead of statutory guidance in December. The Mental Health Network will be responding to that consultation, and will be seeking member views to input into our response.

For more information on the issues covered in this *Briefing*, contact: rebecca.cotton@nhsconfed.org

Key questions for boards

For mental health providers:

- What training do our staff have in autism awareness?
- What reasonable adjustments do we make in our services to meet the needs of adults with autism?

For commissioners:

- Do we have a local lead on the development of a diagnostic and assessment pathway and service?
- Have our PCT and local authority addressed autism as part of the joint strategic needs assessment?
- What specialist expertise and support do we have locally to support adults with autism from across the spectrum?

For all organisations:

- What information do we collect on adults with autism and how can we share this between services to inform planning?
- What is our role in the development of regional plans?
- Have our PCT and local authority set up an autism planning group, partnership board or similar, and how can we get involved?

References

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The Mental Health Network

The Mental Health Network was established as part of the NHS Confederation to provide a distinct voice for mental health and learning disability service providers. We aim to improve the system for the public, patients and staff by raising the profile of mental health issues and increasing the influence of mental health and disability providers.

For further details about the work of the Mental Health Network, visit www.nhsconfed.org/mhn or email mentalhealthnetwork@nhsconfed.org

The National Autistic Society

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism. The NAS was founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. Today the society has nearly 20,000 members, 90 branches and provides a wide range of advice, information, support and specialist services to 100,000 people each year.

The NAS can provide training in autism, help share best practice in autism services, support the involvement of local parents and people with autism in planning and developing services as well as helping local agencies to implement national policies. The NAS has regional offices across the country who can provide local support.

For more information about the support NAS can offer locally, or for more details on any aspect of the strategy, please email policy@nas.org.uk Updates on the strategy are available at www.autism.org.uk/dhstrategy

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NHS CONFEDERATION



The NHS Confederation
29 Bressenden Place London SW1E 5DD
Tel 020 7074 3200 Fax 0844 744 4319
Email enquiries@nhsconfed.org
www.nhsconfed.org

