

Fulfilling and rewarding lives: A briefing on the National Adult Autism Strategy for England



Phil Hope

Fulfilling and rewarding lives is the Government's first ever strategy for adults with autism¹ in England.

The strategy was published on 3rd March 2010. A full copy of the strategy can be found at www.autism.org.uk/dhstrategy

Key actions from the strategy include:

1. Improved training of frontline professionals in autism
2. The recommendation to develop local autism teams
3. Actions for better planning and commissioning of services, including involving people with autism and their parents/carers
4. Actions for improving access to diagnosis and post-diagnostic support
5. Leadership structures at national, regional and local levels for delivery
6. Proposals for reviewing the strategy to make sure that it is working

1. Improved training of frontline professionals in autism

Awareness and understanding of autism among professional is poor. For example, the recent National Audit Office report on *Supporting people with autism into adulthood* found that 80% of GPs did not feel that they had a good understanding of autism.

The strategy sets out a number of actions and recommendations to address the lack of awareness of autism among frontline staff, including:

- Work to ensure that autism is included in the core training curricula for doctors, nurses and other clinicians
- Autism training to be part of training for staff carrying out community care assessments
- Autism awareness training for all working in the public sector
- £500,000 to fund a training programme to improve understanding of autism among frontline professionals in health and social care
- Programmes of work to support training at a local level
- Training in autism for all Disability Employment Advisors (DEAs)

¹ The term autism is used throughout to refer to all diagnoses of autism, including Kanner autism, classic autism, Asperger syndrome, high functioning autism and pervasive developmental disorder (PDD).

2. The development of local autism teams

Currently where services are working at a local level for adults with autism, this has largely been as a result of the development of local autism teams. These teams provide support to mainstream services to help them to support adults with autism.

These teams also help ensure that those adults who have an IQ above 70 (and therefore do not qualify for support from the learning disability team) or who do not have a significant co-occurring mental illness (and so do not qualify for support from mental health teams) do not “fall in the gap” created by traditional service boundaries.

The strategy recognises the importance of local autism teams and encourages local services to develop these teams.

To support this the Government will ensure that local best practice examples are shared as the implementation of the strategy is taken forward.

3. Actions for better planning and commissioning of services, (including involving people with autism and their parents/carers)

Information on the needs of local people with autism has been poor, meaning that local authorities and primary care trusts (PCTs) have been failing to develop appropriate services.

The strategy seeks to address this through:

- A commitment to change the guidance on the development of local “Joint Strategic Needs Assessments (JSNAs)” to include autism. JSNAs are a a planning tool that every local area must produce. Including autism in the JSNA will help ensure that appropriate services will be developed locally for adults with autism
- The development of a protocol of what information should be recorded locally on the needs of adults with autism and how it should be shared between services
- Establishing the importance of involving people with autism and their family/carers in the development and delivery of services
- Encouraging the development of local autism partnership boards *“that bring together different organisations, services and stakeholders locally and set a clear direction for improved services”*.

4. Actions for improving access to diagnosis and post-diagnostic support

Access to diagnosis for adults with suspected autism is poor. There is a real lack of local diagnostic services² and GPs have said they do not have the expertise to identify people with suspected autism for referral even if there was somewhere for them to refer onto. Without a diagnosis adults with autism can find it very difficult to access support.

Moreover diagnosis is often carried out in isolation with no subsequent development of a personalised package of support.

² The NAS services directory identifies only 14 NHS teams/individuals who provide diagnosis and assessment for adults – all of these only diagnose on referral and some will only diagnose those with a learning disability.

The strategy seeks to address this issue by:

- Recommending the local appointment of a lead professional to develop a local diagnostic and assessment services for adults with suspected autism
- Committing the National Institute of Clinical Excellence (NICE) to developing model care pathways to form the foundation of local referral and care pathways
- 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

5. Leadership structures at national, regional and local levels for delivery

A lack of leadership at all levels on autism has been a key barrier to the development of services for adults with autism.

In a letter to MPs on the Autism Bill, Minister of State for Care Services Phil Hope set out that the Valuing People Now model for national, regional and local leadership would be replicated in the autism strategy.

As well as ensuring that services are taking responsibility for adults with autism, this is also important to ensure that local services are able to access the support they need to deliver on the aspirations of the autism strategy.

The strategy states that:

- Directors of Adult Social Services should ensure that there is a **joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism**
- At a regional level, **DH will work with the Association of Directors of Adult Social Services (ADASS), strategic health authorities, local government offices, deputy regional directors and other key partners to support the development of a regional delivery plan for adults with autism in each government region.**
- More details on regional plans will be set out in the delivery plan, which is due to be published by 31st March 2010
- At a national level, the Minister for Care Services and the Director-General of Social Care at the Department of Health will co-chair a "National Programme Board", which will oversee the implementation of the strategy. The board will include representatives from other government departments as well as stakeholder groups.

6. Proposals for reviewing the strategy to make sure that it is working

It is important that the implementation of the strategy is kept under review and that the strategy can be revised as necessary.

To address this the Government has committed to formally review the strategy in 2013 and take action if the improvements set out in the strategy are not delivered.