

# Summary of the Initial Report by the External Reference Group for the Adult Autism Strategy for England

May 2009

## **Foreword**

All adults with autism<sup>1</sup> deserve to get the support and services they need to fulfil their potential. I know that far too often adults with autism are let down, and are unable to access the kind of support that would make a real difference to their lives and the lives of their families. This is not acceptable.

For this reason, I am pleased that the Government is producing a strategy to improve the lives of adults with autism. They need your help to make sure they get the strategy right - this is important because local authorities and NHS bodies will need to act on what the strategy says.

To help develop the strategy, the Department of Health set up an External Reference Group (ERG) at the end of 2008. Members of the group include adults with autism, carers, professionals and voluntary sector organisations. As a group we have been working hard to write a report which sets out what we think needs to change, so that all adults with autism can get the support they need. Today, I am delighted to be publishing this summary of our initial report of recommendations for the adult autism strategy for England. The full report is also being published alongside this summary. The views expressed in both the summary and full report are of the ERG and not the Department of Health or other Government departments.

We are publishing this summary because we thought you might like to read our ideas for improving services for people with autism. We thought you might find it useful if you are taking part in the consultation. You may agree, or disagree, and you may have other ideas. Whatever your view, I hope you will tell the Government what you think should happen. For more details about the consultation, please go to the Department of Health website or the websites of the charities involved in the ERG.

I am looking forward to getting involved in the consultation. At the same time, the ERG will be finalising its report, which we will submit to the Department of Health in September. This will help inform the strategy, alongside your contribution.

If you ever wanted to tell the Government how they can make life better for adults with autism, here is your chance. We in the ERG have told them what we think. Now it is your turn.

### **Mark Lever**

Chair of the External Reference Group for the Adult Autism Strategy for England and Chief Executive of The National Autistic Society

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<sup>1</sup> The term 'autism' is used here to refer to diagnoses across the autism spectrum, including Asperger syndrome and high-functioning autism. Throughout the rest of the report, autism spectrum disorder or ASD is used.

## **Introduction**

The recommendations in this report fall into the following five themes.

1. Health (including diagnosis, post-diagnostic support, accessible healthcare and mental health).
2. Social inclusion (including accessing appropriate support, inclusive living, accessing meaningful activities and accessing the physical and sensory environment).
3. Choice and control (including person-centred planning, advocacy, transition planning and involvement in service development).
4. Employment (including access to employment support, awareness of autism in the workplace, access to benefits and access to adult education).
5. Training (including awareness-raising and training of professionals).

The actions outlined below in each of the five sections are key recommendations. However, the group also compiled a much longer list of carefully considered recommendations, which can be found in the full report.

We will be revisiting all of our recommendations over the coming months to make sure that they are the right ones and to consider in detail which should be prioritised.

All of the views expressed in this document are of the External Reference Group and not the Department of Health or other Government departments.

## **General principles**

*Human rights and autism spectrum disorders (ASDs):* The ERG believes that it is essential that the strategy is set within an equality and human rights approach - people with ASD have, and should be able to enjoy the same rights as everyone else on an equal basis. This should apply regardless of co-morbidity, gender, ethnic background, age, religion or sexuality.

*Reasonable adjustments:* The ERG believes that reasonable adjustments should be made to ensure that people with ASD can access the services they need and the community in which they live.

*Involvement:* The ERG believes that people with ASD should be involved in the development of new services and policies that affect them. They should also be involved as far as possible in the design and delivery of training programmes.

## **1. Health**

**Vision for change:** Adults with ASD are able to access a needs- and skills-based assessment (including diagnosis) from suitably-qualified professionals from a multi-agency team. This assessment is used to inform a personalised package of care. All adults with ASD get the health services and support (including mental health services) they need at the place and time they choose.

### **What things are like now**

- **Diagnosis and post-diagnostic support:** A lack of diagnostic services means that the vast majority of adults with ASD (who did not get a diagnosis as a child) remain undiagnosed, and are unlikely to be able to access the services they need. Where diagnosis is available, it is often done in isolation, meaning that post-diagnostic support is not always available and that a needs- and skills-based assessment that feeds into the development of a person-centred package of care is not carried out.
- **Health care service inequalities:** A lack of understanding of ASD among healthcare professionals means that additional health problems are not always recognised. There are also often misunderstandings about co-existing conditions (e.g. dyspraxia). Moreover, if adjustments are not made for a person with ASD, the experience of visiting a health setting can be distressing.
- **Mental Health:** In general, adult mental health professionals do not have the necessary training, expertise and experience in either ASD diagnosis and assessment or in the support needed by people with ASD who have additional mental health needs.

### **Key recommendations**

1) An ASD “hub” or team should be set up in every local area, which will act as a one-stop shop for expertise in diagnosis and service support. The “hub” should be jointly funded by local authorities and Primary Care Trusts (PCTs). Meanwhile, each Strategic Health Authority should establish a regional ASD team, funded through specialist commissioning arrangements.

2) Every PCT must establish an agreed written referral pathway for adults with a suspected ASD to access diagnosis. Multi-agency assessments should form part of this pathway and this assessment should be used to inform the development of a personalised package of support.

3) The Department of Health should instruct the National Institute of Clinical Excellence (NICE) to expand the remit of its current work on the diagnosis of ASD to include adults and the impact of interventions for all age groups

4) Workforce development plans within the NHS must look at the training needs of all health professionals in relation to ASD. This will pay particular attention to mental health professionals and GPs.

5) Local authorities and PCTs must develop measures to identify and keep a record of adults with ASD in their catchment area. PCTs and local authorities must also set up protocols to ensure effective transfer of data on individuals as they move between services, while respecting data protection principles.

6) PCTs and local authorities must ensure that Joint Strategic Needs Assessments (JSNAs) specifically and comprehensively include all the needs of adults with ASD.

7) GPs should identify all people with ASD in their practice and proactively invite them for annual health checks (which include prescription reviews).

8) The Department of Health should produce best practice guidance for healthcare settings, demonstrating the range of adjustments that could be made to support patients with ASD.

9) The Department of Health should support a research and development programme that informs current and future service provision.

## **2. Social inclusion**

**Vision for change:** All adults with ASD are treated as equal citizens and are fully and appropriately supported to fulfil their potential and participate in society as much as they are able. Adults with ASD will no longer fall through the gap between learning disability and adult mental health services. Instead, appropriate, needs-led services will be developed.

### **What things are like now**

- **Appropriate support and access to meaningful activities:** About two-thirds of adults with ASD are unable to access the support they need and the provision of services for people with ASD at a local level is patchy and inconsistent. Barriers to accessing appropriate support include: the structure of social services and local leadership (meaning that people with ASD fall through the gap between learning disability and mental health services), eligibility criteria and a lack of strategic planning.
- **Inclusive/independent living, housing, transport and accessibility:** People with ASD are not always able to access the range of options and support available when choosing to live independently, when looking for housing and when participating in their wider preferred community. Large numbers of people with ASD are dependent on their families and continue to live in the family home. Independent living skills training is not widely available. Moreover, transport is often inaccessible for people with ASD and public buildings and spaces can also be inaccessible.

### **Key recommendations**

- 1) Local authorities and PCTs must develop measures to identify and keep a record of adults with ASD in their catchment area **(see 'Health' action 5)**.
- 2) Local authorities must implement the Director of Adult Social Services' guidance and appoint a named individual with responsibility for ASD. This lead will have responsibility on behalf of the local authority to set up an ASD team or "hub" in their local area **(see 'Health' action 1)**.
- 3) Local authorities and PCTs must invest locally in specific services that help tackle social exclusion among adults from across the autism spectrum. This will include social skills training, social groups, job preparation schemes and befriending, as well as other specific supportive programmes (e.g. transport training, awareness and training programmes on how to access housing/ employment/social care/ healthcare). It may also include assigning a family support worker or a lead professional to every individual with ASD in a local area. Such services should be available to all people with ASD, regardless of whether they are eligible for support through Fair Access To Care Services (FACS).

4) Local authorities should make sure that their housing strategy incorporates the range of needs of adults with ASD (including environmental and sensory needs), looks at the adaptations that may need to be made for an adult with ASD and guarantees that people with ASD can have a real choice over where they live. Local authorities should involve people with ASD in developing their strategies.

5) All community care assessments (and FACS assessments, where these are carried out separately) must be carried out by a professional with training and expertise in ASD to ensure that a full assessment of need is undertaken. Where training has not yet been completed, staff carrying out assessments should seek assistance from local partners (such as third-sector organisations) with expertise in ASD.

6) Local authorities should review the operation of their local FACS policy in the light of the CSCI findings<sup>2</sup> to ensure that it does not discriminate against adults with ASD.

7) The Department of Health should work with other relevant Government Departments to develop measures to ensure that transport, housing, workplaces and other environments are made accessible for people with ASD. This will also include making sure that accessible formats of policy documents and consultation documents are made available.

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<sup>2</sup> Commission for Social Care Inspection. (2008). *Cutting the Cake Fairly. CSCI review of eligibility criteria*. London: CSCI.

### **3. Choice and control**

**Vision for change:** All adults with ASD are given the support they need to be empowered to take control of their lives, participate as much as they are able in society and pursue the lifestyle and relationships they choose.

#### **What things are like now**

- **Personalisation:** Adults with ASD are less likely than other people with disabilities to have support plans that are holistic and meet their unique needs. Only 27% of adults with ASD currently have a person-centred plan or care plan. Adults with ASD currently lack choice and support when choosing to live independently, when looking for employment, when accessing higher education and when participating in their wider community. The involvement of adults with ASD in policy-making and service planning is not standard practice and can be tokenistic.
- **Transition planning:** There is a high level of dissatisfaction with the process of transition to adult services. If transition fails, adults often find themselves embedded more firmly in the family home, which can result in them leading isolated lives and increasing stress on families.
- **Advocacy and self-advocacy:** Advocates are not widely available and generally do not have a good understanding of ASD. There is also a lack of skills training in self-advocacy.

#### **Key recommendations**

1) Local authorities and PCTs must involve relevant ASD user-led organisations, other third-sector organisations, adults with ASD and their families in local decision-making and in the development of new relevant services, in line with commitments under the Disability Equality Duty. Meanwhile, The Department of Health should develop national forums for the involvement of people with ASD in the development of national policy that will impact on them.

2) Local authorities and their partners should build capacity around person-centred approaches and planning so that all adults with ASD and their families have informed support to develop, and continue to develop, person-centred plans. These plans will identify what is important to them - now and in the future - and what support they need to achieve their aims and goals. Adequate provision should also be made for those people whose family, for whatever reason, cannot or should not be involved.

3) Through collaboration with existing advocacy groups, local authorities should ensure that there are advocates in their area who are able to appropriately support people with ASD. This should include Independent Mental Capacity Advocates (IMCAs), established under the Mental Capacity Act.

4) Government offices, through regional ASD teams (**see 'Health' action 1**) where appropriate, should work with local service commissioners and providers to develop systems and processes that enable people with ASD to build and sustain personal relationships.

5) The Department of Health, local authorities and PCTs should make sure that any ASD training programmes they develop highlight the importance of the communication needs of people with ASD and the importance of supporting people to communicate in the way that they choose. This will include raising awareness of Augmentative and Alternative Communication (AAC).

6) Local authorities and their partners must comply with their statutory duties to ensure a proper transition to adulthood for young people with ASD, including those under the SEN Code of Practice and the regulations and guidance for care leavers. Transition plans should also be made available for all young people who have a special education need as a result of having ASD, but who do not have a statement of special educational needs.

7) All local authorities must ensure that their Resource Allocation Systems (RAS) for personal budgets can make an accurate and fair account of the needs of adults with ASD. This will include ensuring that people with ASD are consulted when local authorities are developing a RAS.

## **4. Employment**

**Vision for change:** All adults with ASD have the opportunity to work and can access the support they need from benefits and tax credits. Further, higher and lifelong learning opportunities are accessible to adults with ASD.

### **What things are like now**

- *Work:* Only 15% of adults with ASD are in full-time employment, yet a much greater number of people with ASD want to work and could work if given appropriate and timely support.
- *Employers:* Awareness is low among employers of the valuable skills that people with ASD have to offer in the workplace.
- *Benefits and tax credits:* There is a lack of evidence to show how many people with ASD are accessing the benefits for which they are eligible. Anecdotally, people with ASD are not accessing the benefits they need.
- *Education and training:* There is a lack of support for adults with ASD in accessing further, higher or lifelong learning opportunities.

### **Key recommendations**

1) Multi-agency employment strategies in every area, linked to PSA 16, must be inclusive of people with ASD.

2) The Department for Work and Pensions (DWP), through Jobcentre Plus, must introduce mandatory ASD training for all disability employment advisors. The DWP should also ensure that all Jobcentre Plus and Pension, Disability and Carers Service decision-makers receive ASD training.

3) The Equality and Human Rights Commission should publish guidance on the reasonable adjustments employers should make when interviewing a person with ASD and adjustments they must make to the workplace.

4) The DWP must commission specialist employment support for people with ASD. This support must include preparation for work and in-work support. Support should be available regardless of whether the work is paid or unpaid.

5) DWP contracts for specialist ASD employment support should include payments based on progression towards work as well as job outcomes to ensure that providers have an incentive to deliver support to those furthest from the workplace.

6) The DWP should monitor the number of people with ASD receiving Jobseeker's Allowance and Employment and Support Allowance. This data should be used to help evaluate the accessibility of these benefits for people with ASD.

## **5. Training**

**Vision for change:** The general public is aware of and understands ASD, with myths surrounding the condition addressed. All professionals who come into contact with people with ASD are suitably trained and have a particular understanding of the communication, sensory and accessibility needs of adults with ASD. Training for professionals should be accredited and support best practice and available evidence, as well as social inclusion. It should be competently delivered and have links with academia. It should be monitored and evaluated in terms of its impact.

### **What things are like now**

- *General awareness:* Understanding among the general public of the characteristics of ASD and how this can affect behaviour is low, leading to intolerance, discrimination and isolation. In a survey by The National Autistic Society, 83% of individuals with Asperger syndrome felt strongly or very strongly that many of the problems they faced were a direct result of others not understanding them.
- *Awareness among professionals:* Training in ASD and awareness of the condition among professionals that provide support to people with ASD, or who come into contact with them for other reasons, is poor. For example, 71% of local authorities do not think that care managers receive sufficient training in ASD in their initial professional training.

### **Key recommendations**

*We identified over 60 specific groups of people as needing greater awareness of ASD and specific training in ASD. The groups, and the level of training we believe they require, are set out in the appendix of the main report.*

- 1) The Department of Health must work with relevant agencies and bodies to support the development of standards for accreditation of appropriate tiered training programmes to develop expertise. The accreditation programme should be independent, transparent and inclusive.
- 2) Local authorities and PCTs should carry out an audit of the current training programmes and workforce development programmes in their area in relation to ASD. This should inform the development of a local ASD training strategy.
- 3) The Department of Health should fund a national awareness campaign on ASD, which will include promoting positive images of ASD.
- 4) The Department of Health should host a high-level national training summit. The summit will bring together all relevant agencies from health and social care and partner organisations to examine the best ways to improve training and workforce

capacity in relation to ASD. This will include the development of specialist expertise in ASD in a range of sectors.

5) Local authorities and PCTs must ensure that those carrying out Community Care Assessments, FACS assessments or NHS Continuing Care Assessments receive specific training in ASD. Where staff carrying out assessments have not yet received training, they should seek assistance from local partners (such as third-sector organisations) with expertise in ASD. A similar arrangement must be in place for social care brokers.

6) The Department of Health must work with those with responsibility for the provision and regulation of undergraduate and postgraduate social work training to ensure that their curricula include mandatory training in ASD.

## **External Reference Group Members**

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