



National Audit Office

# Supporting people with autism through adulthood

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# SUMMARY

**1** Autism is a lifelong developmental disability, sometimes referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC). Its causes are not fully understood, although there is some evidence that genetic factors are involved. The term 'spectrum' is used because, while all people with autism share three main areas of difficulty (**Box 1**), their condition affects them in different ways. Some can live relatively independently – in some cases without any additional support – while others require a lifetime of specialist care.

**2** Owing to variable identification rates and a general lack of data, it is difficult to quantify with certainty the number of people with autism. Recent estimates suggest that there are about half a million people with autism in England, of whom around 400,000 are adults,<sup>1</sup> and that autism is three to four times more common in men than in women.<sup>2</sup> Uncertainty about the prevalence of autism means that it is also difficult to estimate its associated costs precisely. 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). Of the £25.5 billion cost for adults, 59 per cent is accounted for by services, 36 per cent by lost employment for the individual with autism, and the remainder by family expenses.<sup>3</sup>

1 Knapp et al., *The Economic Consequences of Autism in the UK* (Foundation for People with Learning Disabilities, 2007).

2 Baird, G, Simonoff, E, Pickles, A, et al., 'Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)' in *The Lancet* 368 (2006), 210-215.

3 Knapp et al., *The Economic Consequences of Autism in the UK*.

3 Although the needs of adults with autism vary between individuals, in England the services they require will usually be the responsibility of one of four government departments: the Department of Health, the Department for Children, Schools and Families, the Department for Work and Pensions, and the Department for Innovation, Universities and Skills (Figure 1 overleaf). Individual policy responsibilities of a number of other departments may also be relevant to people with autism, for example the Department for Communities and Local Government *Supporting People* programme, which delivers housing-related support services for vulnerable individuals.

4 This report examines the range of services for adults with autism and their carers in England, including health and social care, education, benefits and employment support. It focuses on services for adults rather than children because children's services are currently more developed than those for adults, and have also been examined in depth in other recent investigations such as *The Bercow Review*.<sup>4</sup> There is, however, much evidence that the transition from children's to adult services can be difficult for people with autism and their carers, and hence our study also covers arrangements for transition planning, which starts formally at age 14.

## Main findings

5 People with autism may use a very wide range of public services, as shown in Figure 1. The data available on the numbers of people with autism using services is limited, so drawing conclusions on the differential effectiveness of service provision as a whole, by comparing outcomes for people with autism with outcomes for people who do not have autism, is difficult. Nevertheless, our analysis suggests that there are two key areas where the effectiveness of existing services can be improved: **better strategy and planning, based on good information** and **raising levels of knowledge and awareness of the nature of autism and the potential needs of autistic people**. Addressing these two issues could improve outcomes for this group by making better use of existing resources.

6 There is also scope for **better targeted support for people with high-functioning autism/Asperger Syndrome**. Such people may not be eligible for the learning disability services available to people with low-functioning autism, as well as being unable to access other support services unless they have a physical disability or a mental health problem.

7 We explored the possible impacts of providing specialised health, social care and employment support for adults with high-functioning autism. Wider implementation of such services would require additional expenditure, for example an estimated £40 million per year by Primary Care Trusts and Local Authorities to provide specialised health and social care teams across the whole of England. Evidence from existing specialised services does however indicate that they can improve outcomes for service users, and our model suggests that the costs could over time be outweighed by overall public expenditure savings.

### BOX 1

#### The features of autism

- The three main areas of difficulty experienced by all people with autism are:
  - communicating socially, particularly using and understanding facial expressions, tone of voice and abstract language;
  - recognising or understanding other people's emotions and feelings, and expressing their own, making it more difficult to fit in socially; and
  - understanding and predicting other people's behaviour, making sense of abstract ideas, and imagining situations outside their immediate daily routine.
- Other related features can include: love of routines and rules, aversion to change, and sensory sensitivity (for example a dislike of loud noises).
- Around half of people with autism also have a learning disability (sometimes known as 'low-functioning'<sup>1</sup> autism), while the rest do not (so-called 'high-functioning' autism, which includes **Asperger Syndrome**).

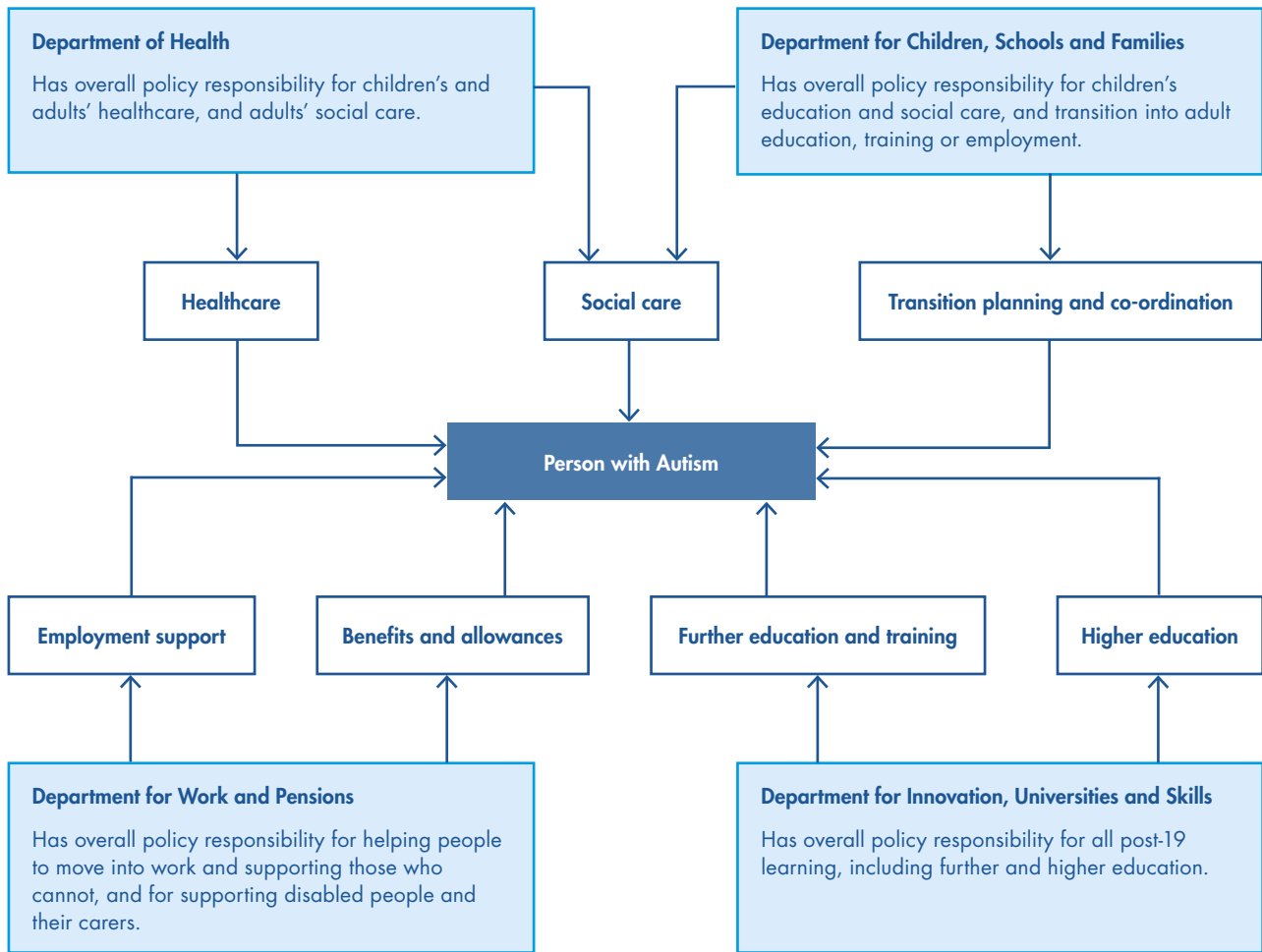
Source: Lorna Wing, *The Autistic Spectrum: A Guide for Parents and Professionals* (adapted)

#### NOTE

1 Current social care policy is based on a 'social' model of disability, which emphasises the need for person-centred approaches focusing on individual needs rather than diagnostic 'labels'. Where our report refers to the terms 'high-' and 'low-functioning', this is to reflect differences in services and eligibility criteria, or to inform assumptions used in our financial modelling (Appendix 2), rather than to suggest that people with autism should be categorised as two distinct groups.

4 Department for Children, Schools and Families, *The Bercow Report: A Review of Services for Children and Young People (0–19) with Speech, Language and Communication Needs* (July 2008).

**1** Main government departments with responsibilities for young people and adults with autism



Source: National Audit Office

**NOTE**

Although this report focuses on the role of these four key departments in providing services to people with autism, a number of other departments have policy responsibilities which may be relevant to this group. For example, the Department for Communities and Local Government's *Supporting People* programme aims to improve the quality of life of vulnerable people (which may include those with autism) through the provision of housing-related services supporting independent living.

**8** A key factor would be the proportion of the local population with high-functioning autism identified by specialised services and given appropriate support, for example to live more independently or to obtain and retain employment. We estimate that if such services identified and supported around four per cent or more of the adults with high-functioning autism in their local area, they could become cost-neutral across public spending as a whole over time, as well as resulting in additional earnings and reduced expenses for individuals.

**9** Increasing the identification rate further could result in greater financial benefits over time. On a number of key assumptions, for example regarding housing settings and employment rates, some of them based on limited data, our model suggests that a six per cent identification rate could lead to potential savings of £38 million per year, and an eight per cent rate to savings of £67 million. Further work is needed to quantify the potential costs and benefits more precisely, and to explore in more detail the potential impacts of implementing such services.

## Conclusion on Value for Money

**10** Better outcomes for people across the whole autism spectrum could be achieved by greater awareness of autism in strategic planning, and better knowledge amongst those responsible for assessing and meeting the needs of people with autism. These improvements, although difficult to quantify, would help to target resources more effectively to meet the needs of this group.

**11** Providing specialised support to adults with high-functioning autism can improve outcomes for this group, including additional earnings and reduced expenses for the individuals concerned. Achieving this improvement would potentially require significant changes to existing service delivery arrangements, with the creation of new roles and new ways of joint working between organisations. There would be costs in implementing such services more widely, but also savings, though the benefits may be realised by delivery partners elsewhere in the system rather than by the lead organisation funding the service. Local health and social care organisations and Jobcentre Plus would therefore need to work together in developing services, for example through pooled health and social care budgets and joint commissioning arrangements.

## Conclusions and Recommendations

**12** On the basis of our examination, we recommend that action needs to be taken to improve outcomes for adults with autism in three main areas.

**a** *The organisations responsible for supporting people with autism need better awareness of the number of people with autism, both to plan and deliver services appropriately, and to measure how effectively services are meeting the needs of this group.*

- i** **Most NHS organisations and Local Authorities lack robust data on numbers of people with autism in their area, thus limiting their ability to identify need, plan capacity and commission appropriate services. Only 18 per cent of Local Authorities and NHS partners responding to our survey were able to give precise numbers of adults with low-functioning autism known to services, while only 12 per cent could do so for the high-functioning group.**

NHS organisations and Local Authorities should collate existing data from learning disability and mental health services to identify and record all adults with autism known to services in their area. **Directors of Children's and Adult Services** should forecast future demand for services by collating and sharing routine Schools Census data, covering numbers of pupils with Statements of Special Educational Needs and at School Action Plus who have autism and are approaching school-leaving age.

The **Department of Health** should build on the results of its planned prevalence work to develop Local Authority and NHS commissioning guidance, including tools for calculating expected levels of prevalence. Local organisations should use these tools to assess where they are at most risk of not identifying autism or meeting the needs of people with autism and their carers.

- ii** **Managing the transition of young people with autism from childhood to adult services requires effective planning and joint working between health, social care, education and employment organisations. The Special Educational Needs code of practice requires every child with a Statement of Special Educational Need to**

**have a transition plan prepared in year nine of compulsory education. Only 45 per cent of Local Authorities responding to our survey told us they knew how many children with autism and a Statement of Special Educational Needs had a completed transition plan. The Department for Children, Schools and Families has recently contracted with the Council for Disabled Children and partners to provide a National Transition Support Team to improve the experience of disabled young people and their families at transition.**

The **National Transition Support Team** should use its local area self-assessment work to identify good practice in transition planning for young people with autism, as well as to identify those local areas where this group is at risk of poor transition. Its advice to the Department should include specific reference to young people with autism and the improvements needed locally to support them.

- iii** **The Connexions service, which supports young people with a learning difficulty or disability through transition and into further education, training and work up to the age of 25, did not know the training, employment or education status of 31 per cent of these clients as at December 2008. Only one quarter of parents surveyed in 2006 felt that transition support was coordinated, and one in three felt that Connexions' knowledge of autism was not adequate.**

As part of their new role in providing Connexions services from 2008-09, **Local Authorities** could provide specific training in autism to their Connexions personal advisors. The **Department for Children, Schools and Families** should require all Connexions services to provide complete and comparable data from the Connexions Client Caseload Information System (CCIS), and use this data to benchmark how well local services are supporting people with autism up to the age of 25, including those not in education, employment or training.

- iv **Around 65 percent of Local Authorities and NHS bodies responding to our survey have difficulty finding appropriate residential placements and supported housing for adults with autism within their area. Over 90 per cent were unable to give us figures for expenditure on out-of-area inpatient services for adults with autism, and over two thirds were not able to estimate their expenditure on out-of-area residential care for adults with autism. While a small number of people with particularly complex needs may need specialised resources that cannot be provided in-area (for example forensic mental health services), for others appropriate support could often be provided locally at lower cost.**
- b *Service providers need a better understanding of what autism is and of the range of potential needs of people with autism, to enable them to meet those needs more effectively with better targeted, more appropriate services.*
- vi **Only 29 per cent of Local Authorities responding to our survey said training for staff assessing eligibility for care services covered high-functioning autism. Eighty per cent of GPs feel they need additional guidance and training to manage patients with autism more effectively.**

The **Department of Health** should draw up good practice guidelines for commissioning support for adults with autism out-of-area, and encourage **Local Authorities, Primary Care Trusts** and **NHS Mental Health Trusts** to review the appropriateness and cost-effectiveness of their long-term out-of-area residential and inpatient placements of people with autism. **Strategic Health Authorities** should formulate strategic plans for managing out-of-area provision commissioned across their regions, including planning to develop the provider market, and drawing on pooled information on the costs and outcomes of residential services across geographical and sectoral boundaries.

- v **The current reconfiguration of health and social care provision with greater emphasis on personalisation presents a good opportunity to help people with autism obtain more appropriate services. There are also risks to be managed, however, as people with autism may need support to manage personal finances and relationships with providers.**

As part of its forthcoming autism strategy, the **Department of Health** should provide guidance to Local Authorities on: appropriate quality control of individual services that people with autism may use; supporting people with autism and their carers to manage their financial and contractual arrangements, and providing people with autism and their carers with sufficient information to make informed choices about available services.

The **Department of Health** should provide guidance to Primary Care Trusts on how to improve knowledge and awareness of autism amongst GPs and other primary care practitioners. Local Authorities should provide specific training in autism to all staff carrying out community care assessments. Where staff have not yet received such training, Local Authorities should identify appropriate local partners (such as third-sector organisations) with autism expertise to assist with the assessment process.

- vii **People with autism and their carers report that Department for Work and Pensions employment support services do not always meet their needs. Although training for Disability Employment Advisors now includes autism-specific content, the initial training received by around 200 of the 500 Disability Employment Advisors currently in post did not cover autism.**

The **Department for Work and Pensions** should provide awareness training in autism for Disability Employment Advisors whose initial training took place prior to November 2005, including advice on how to communicate effectively with people with autism and their carers to identify their needs, and work effectively with specialist autism organisations to meet them.

In developing the Government's autism strategy, the **Department of Health** and **Department for Work and Pensions** should work together to appraise the costs and benefits of different models for providing specialised employment support appropriate to the needs of adults with autism. They should identify how these models could be integrated within local structures developed to deliver the *Valuing People Now* strategy for people with learning disabilities<sup>5</sup> and the forthcoming cross-government Public Service Agreement Target (PSA) 16<sup>6</sup> employment strategy.

**viii People with autism can have valuable skills to offer employers, but employment rates for people with autism are low, with many finding lack of understanding of autism amongst employers a significant barrier to work.** Recent estimates suggest that only 15 per cent of adults with autism are in full-time employment.<sup>7</sup> Yet with appropriate awareness training and support, a number of employers have successfully integrated people with autism into their workforce.

The **Department for Work and Pensions** should work at a national level with employer organisations such as Employers' Forum on Disability to raise awareness amongst employers of the potential benefits of employing people with autism, and what adjustments might be needed to support them.

**ix Robust routine data on retention and achievement rates for students with autism has been limited to date, but evidence from Disability Support Officers suggests that, with appropriately targeted support, they can complete their courses with good results. There is, however, some lack of understanding amongst university disability advisors and students as to whether Disabled Students' Allowances can be used to fund the social mentoring needed for students with autism.**

The **Department for Innovation, Universities and Skills** should make clear to Disabled Students' Allowances assessors and higher education disability advisors that a support package for a student with autism can legitimately include social mentoring as well as course-related support.

**c** *Better-targeted specialised provision for adults with high-functioning autism/Asperger Syndrome, both diagnostic services and post-diagnostic support, has the potential to lead to improved quality of life for people with autism and their carers, as well as improving the cost-effectiveness of current service provision.*

**x Adults with high-functioning autism and Asperger Syndrome often struggle to obtain a diagnosis, and owing to eligibility criteria or lack of provision, frequently fail to access either learning disability or mental health services. Only 10 per cent of Local Authorities and NHS bodies responding to our survey commission ongoing support for high-functioning autism from specialist teams, yet the 'preventative' support which they provide could enable more adults with autism to live relatively independently in the community.**

The **Department of Health** should build on our modelling to show Local Authorities and NHS organisations the costs and benefits of specialised diagnostic and support services for high-functioning autism. Its forthcoming autism strategy should set out good-practice examples of how to deliver such support, with particular reference to reducing social isolation and mental health difficulties, developing independent living skills and relationships, providing appropriate housing, and offering information and support for carers. The strategy should indicate the sort of outcomes which Local Authorities and NHS bodies should be aiming to achieve, and how performance in supporting adults with autism should be assessed. It should also emphasise the need for local bodies to co-ordinate the funding and development of such services, for example through pooled budgets and joint commissioning.

5 Department of Health, *Valuing people now: a new three-year strategy for people with learning disabilities* (19 January 2009). ([http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093377](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377)).

6 Cabinet Office, *PSA Delivery Agreement 16: Increase the proportion of socially excluded adults in settled accommodation and employment, education or training* (October 2007) ([http://www.cabinetoffice.gov.uk/media/cabinetoffice/social\\_exclusion\\_task\\_force/assets/chronic\\_exclusion/psa\\_da\\_16.pdf](http://www.cabinetoffice.gov.uk/media/cabinetoffice/social_exclusion_task_force/assets/chronic_exclusion/psa_da_16.pdf)).

7 National Autistic Society, *Think Differently, Act Positively – Public Perceptions of Autism* (2008), p. 19 (<http://www.autism.org.uk/content/1/c6/01/47/21/think%20diff%20act%20pos.pdf>).