National Audit Office

Supporting people with autism through adulthood

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL | HC 556 Session 2008-2009 | 5 June 2009

The National Audit Office scrutinises public spending on behalf of Parliament. The Comptroller and Auditor General, is an Officer of the House of Commons. He is the head of the National Audit Office which employs some 850 staff. He and the National Audit Office are totally independent of Government.
He certifies the accounts of all Government departments and a wide range of other public sector bodies; and he has statutory authority to report to Parliament on the economy, efficiency and effectiveness with which departments and other bodies have used their resources. Our work leads to savings and other efficiency gains worth many millions of pounds: at least £9 for every £1 spent running the Office.

The NAO have produced a DVD illustrating the themes covered in this report. Its content can be viewed at www.nao.org.uk/autismdvd, and copies of the DVD can be obtained via enquiries@nao.gsi.gov.uk

Design and Production by
NAO Marketing & Communications Team
DP Ref: 008918
This report has been printed on Consort Royal Silk and is produced from a combination of ECF (Elemental Chlorine Free) and TCF (Totally Chlorine Free) wood pulp that is fully recyclable and sourced from carefully managed and renewed commercial forests. The range is manufactured within a mill which is registered under the BS EN ISO 9001 accreditation, which provides the highest standard of quality assurance.

FSC

CHLORINE FREE
ECF

CHLORINE FREE
TCF

Supporting people with autism through adulthood

A report by the Comptroller and Auditor General

Published by TSO (The Stationery Office) and available from:

Online
www.tsoshop.co.uk

Mail, Telephone, Fax & E-mail
TSO
PO Box 29, Norwich, NR3 1GN
Telephone orders/General enquiries: 0870 600 5522
Order through the Parliamentary Hotline
Lo-Call 0845 7 023474
Fax orders: 0870 600 5533
E-mail: customer.services@tso.co.uk
Textphone: 0870 240 3701

The Parliamentary Bookshop
12 Bridge Street, Parliament Square,
London SW1A 2JX
Telephone orders/General enquiries 020 7219 3890
Fax orders: 020 7219 3866
Email: bookshop@parliament.uk
Internet: http//www.bookshop.parliament.uk

TSO@Blackwell and other Accredited Agents

Customers can also order publications from:

TSO Ireland
16 Arthur Street, Belfast BT1 4GD
028 9023 8451 Fax 028 9023 5401

£14.35

ISBN 978-0-10-295503-3

9 780102 955033

The Stationery Office

National Audit Office

Supporting people with autism through adulthood

LONDON: The Stationery Office
£14.35

Ordered by the
House of Commons
to be printed on 4 June 2009

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL | HC 556 Session 2008-2009 | 5 June 2009

This report has been prepared under Section 6 of the National Audit Act 1983 for presentation to the House of Commons in accordance with Section 9 of the Act.

Tim Burr
Comptroller and Auditor General
National Audit Office

28 May 2009

The National Audit Office
study team consisted of:

Frazer Clark, Jennie Nicholson, Sophia Parveen, Alex Scharaschkin, Louise Sumner, Rowena Tozer and David Xu, with the assistance of Monica Binns, Louise Cardani, Benjamin Charlton, Helen Evans, Chris Grant, Ben Jones, Rashmi Rajyaguru and Simone Tsang, under the direction of Mark Davies

This report can be found on the National Audit Office web site at www.nao.org.uk

For further information about the National Audit Office please contact:

National Audit Office
Press Office
157-197 Buckingham Palace Road
Victoria
London
SW1W 9SP

Tel: 020 7798 7400

Email: enquiries@nao.gsi.gov.uk

CONTENTS

APPENDICES

Photographs courtesy of Mystic Monkey and Ladbroke Grove Autism Centre

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,[1] and that autism is three to four times more common in men than in women.[2] 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.[3]

---

[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*.[4] 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**'[1] 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)

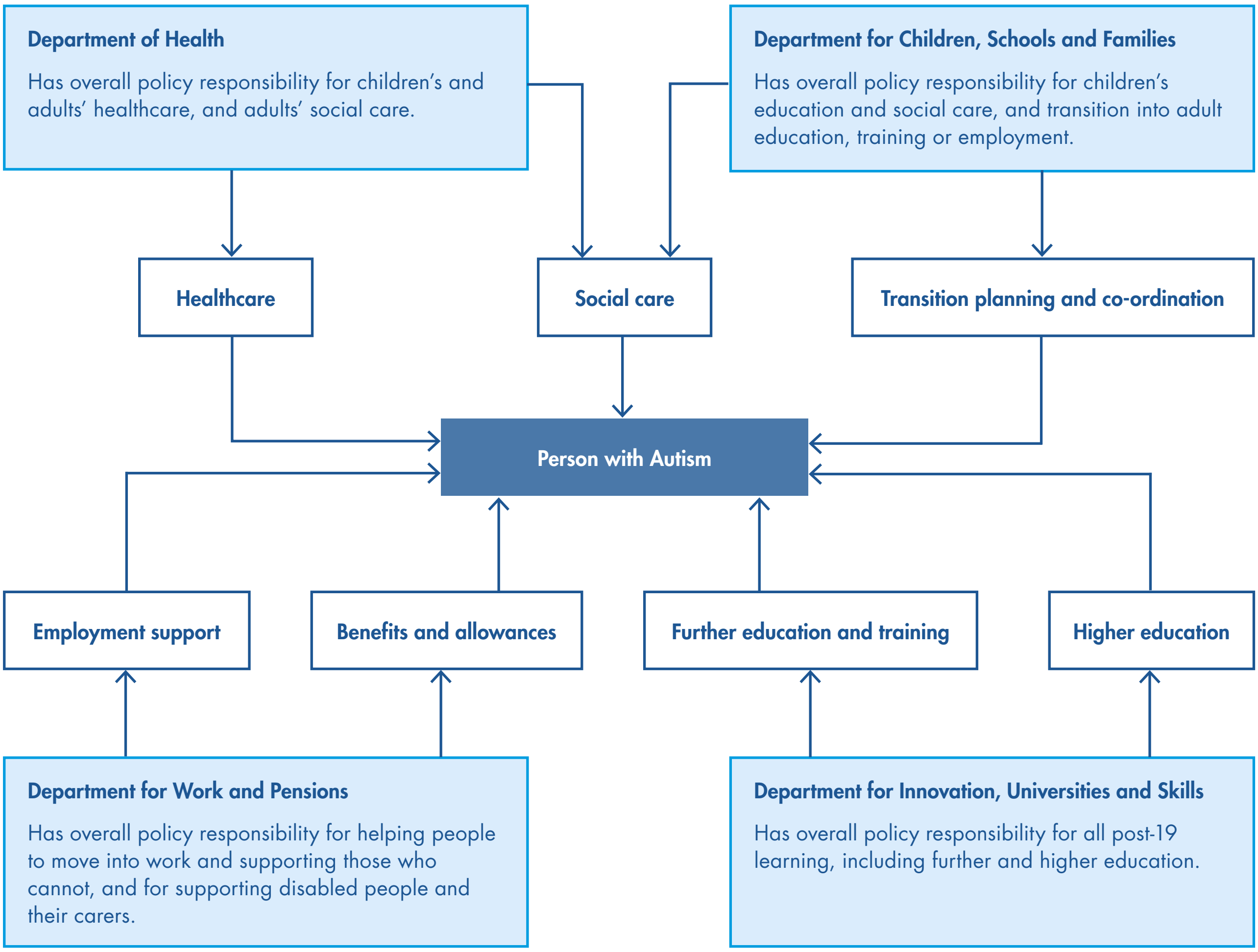
NOTE

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**.

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.

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 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[5] and the forthcoming cross-government Public Service Agreement Target (PSA) 16[6] 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.[7] 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).

[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).

[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%20acrt%20pos.pdf).

Strategy and planning for adults with autism

Scope of this report

1.1 This report examines the effectiveness of support services to 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 other recent investigations such as the *Bercow Review*[8] and the current *Lamb Inquiry*.[9] 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.

What is autism?

1.2 Autism[10] is a lifelong developmental condition, sometimes referred to as Autism 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 word 'spectrum' is used because, while all people with autism share three main areas of difficulty, 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.

1.3 Around half of people with autism also have a learning disability (sometimes known as 'low-functioning' autism), while the rest do not (so-called 'high-functioning' autism, which includes Asperger Syndrome).[11]

1.4 People with Asperger Syndrome and high-functioning autism are affected by the impairments common to all people with autism **(Figure 2 overleaf)**. They may, however, have fewer problems with verbal communication, and it may not be immediately apparent that they have the condition from their outward appearance or behaviour.

1.5 People with autism may also have learning disabilities and learning difficulties, including dyslexia and dyspraxia. While some people with learning difficulties can live independently, others with severe intellectual impairments impacting on adaptive skills in all areas of their lives may require lifelong specialist support. Other conditions sometimes associated with autism include attention deficit hyperactivity disorder (ADHD), or medical conditions such as epilepsy.

1.6 The three main areas of difficulty which all people with autism share relate to 'social communication', 'social interaction' and 'social imagination' (Figure 2). People's difficulties in these areas may be accompanied by other related features, such as a love of routines and rules, or sensory sensitivity (for example a dislike of loud noises, bright lights or certain colours and textures). These difficulties can impact on the lives of people with autism and their carers in many ways, and mean that they require a wide range of support to cope with day-to-day life.

---

[8] 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).

[9] http://www.dcsf.gov.uk/lambinquiry/.

[10] The term 'autism' is used in our report to cover the whole autistic spectrum, including autism, high-functioning autism, Asperger syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). See Glossary for more details.

[11] 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 uses 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.

2 Difficulties experienced by people with autism and their associated support needs

Areas of Difficulty	Needs
Social Communication ■ Difficulty with both verbal and non-verbal language. Although many people with autism have good language skills, some may not speak or have limited speech. While they may usually understand what other people say to them, some will prefer to use alternative means of communication themselves, such as sign language or visual symbol systems. ■ Literal understanding of language, and difficulty using or understanding abstract language, or jokes and sarcasm. ■ Difficulty understanding non-verbal communication such as facial expressions or tone of voice.	Speech and language therapy to facilitate verbal and/or non-verbal communication. Monitoring by trained staff to manage risk of social isolation, mental and physical health problems. Social clubs and coaching in building relationships with friends, classmates, partners and work colleagues. Specialised support in finding and retaining a job, including mentoring and awareness training both for person with autism and their colleagues. Trained support when attending job interviews, or alternative formats such as work trials.
Social Interaction ■ Difficulty recognising or understanding other people's emotions and feelings. It may be difficult for them to fit in socially as they may, for example, appear insensitive or start an 'inappropriate' subject of conversation. ■ Difficulty expressing feelings, emotions, or needs, which can mean their behaviour is seen as strange or inappropriate. They may, for example, prefer to be alone or deal with anxiety by engaging in repetitive behaviour.	Monitoring by trained staff to manage increased risk of social isolation, mental and physical health problems. Social clubs and coaching in building relationships with friends, classmates, partners and work colleagues. Specialised support to find and retain a job, including mentoring and awareness training both for person with autism and their colleagues. Trained support when attending job interviews, or alternative formats such as work trials.
Social Imagination ■ Difficulty understanding and predicting other people's behaviour, making sense of abstract ideas, and imagining situations outside their immediate daily routine. ■ Difficulty interpreting other people's actions, or predicting or imagining what might happen next. ■ Difficulty coping in new or unfamiliar situations, with changes in routine, or planning for the future.	Mentoring to reduce vulnerability to theft or exploitation, and to manage increased risk of physical harm, e.g. crossing the road or facing potentially threatening behaviour. Predictable supportive living and work environment. Mentoring and staged transition support when changing locations, routines or activities (e.g. schools, housing). Mentoring and advice to manage personal finances, housing and self-care/healthcare.
Related Features ■ Ritualistic behaviour; ■ Love of routine and rules; ■ Intense interest in a particular subject; and ■ Sensory sensitivity (e.g. noise, light, texture).	Adapted teaching methods and sensory environments in school, college or university, to reduce risk of drop-out. Environmental adjustments at home (e.g. adapted housing) and in the workplace (e.g. adjustments to layout, lighting, etc). Specialised employment support and awareness training, as above.

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

1.7 Although it is possible to classify in general terms the difficulties of people with autism, the fact that it is a spectrum condition means the range of possible impairments and needs is very large. These illustrative examples show some of the difficulties and support needs of people at various points on the autistic spectrum:

Example One

Adam is 35 years old. He was diagnosed aged five with classic 'low-functioning' autism with a learning disability. Adam attended a special school run by an autism charity from age five to 18. Adam is largely non-verbal and sometimes uses a symbol system to communicate with his carers. Adam also suffers from epilepsy, for which he takes medication.

Adam lives in a residential placement with eight other residents in a service run by a third-sector organisation. This placement is funded out of area by his home Local Authority, with the contract being agreed on an annual basis. Adam attends the day service run by the same third-sector service provider. Here he takes part in music and art classes, life skills, communication sessions, and physical activity. As well as funding Adam's residential placement, his Local Authority has also provided funding for 14 hours per week of one-to-one support for Adam as a result of his communication needs.

Adam receives Disability Living Allowance, which is used to pay for items such as clothing, social trips and a CD player, as Adam enjoys listening to music.

There is a GP attached to the residential service, and Adam is supported to attend annual dentist appointments, as well as consultations with his epilepsy specialist.

Example Two

Bridget is 25 years old. She has a diagnosis of autism and dyslexia, which she received when she was 15. Bridget attended a mainstream school and had a Statement of Special Educational Needs which meant she received classroom support. Bridget went through the transition process into adult services, and on leaving school at 16 went to a work-based training provider to train for an NVQ in administration. During the scheme she was supported by disability support workers at her local FE College. Since finishing the scheme, Bridget has been to the job centre but has been unable to find a job. Although she has shown herself to be efficient at administrative tasks, she has struggled with job interviews, not least because unfamiliar people and physical environments make her extremely anxious. She is more confident in her volunteer work at a local charity, where she does administrative work two days a week and can maintain a strict routine, including travel to and from work and break times.

Bridget receives Jobseeker's Allowance and Disability Living Allowance. At present she lives with her parents, although her father is currently in discussions with the Local Authority to see if they can provide appropriate supported housing with an on-site warden and extra sound-proofing (Bridget sometimes suffers from sensory overload). Bridget attends a regular social group for people with autism, which is run by a charity. She also has a mentor, through a local advocacy scheme, whom she meets once a month.

Example Three

Carl is 39 years old. He was diagnosed with Asperger Syndrome at the age of 30. Carl attended a mainstream school up to age 18, where he excelled at maths and physics. However, he struggled to make friends amongst his classmates, and the other children frequently told him he was 'strange'. He went to university away from home at 18, but found many aspects of university difficult, particularly making new friends, organising his time and money, and attending lectures in large, noisy halls. He became very lonely and unhappy, and after one term decided to drop out and return home to his parents. With the help of his tutor, he was able to arrange a transfer to his local university, which allowed him to study for his degree whilst living in more familiar home surroundings.

Carl left university with a good degree, but found it difficult to find a job. He found interviews particularly difficult, often not knowing what the interviewer meant or being told that he didn't 'come across well'. He remained living at home with his parents, rarely going out and becoming very isolated. He became depressed and suffered a mental health crisis, at which point he was admitted to hospital and misdiagnosed with treatment-resistant schizophrenia. A chance encounter with a consultant psychiatrist who had a special interest in autism led to a revised diagnosis of Asperger Syndrome two years later.

Carl has received support from a specialist Asperger team since his diagnosis, including access to a counselling service. He was able to get support from the Disability Employment Advisor at the job centre to find a job in a local government office, where he has worked for the last six years. He now rents his own flat and lives independently, although he remains in regular contact with his Asperger service caseworker, who keeps an eye on his physical and mental health and helps resolve any issues arising.

Source: National Audit Office

1.8 Although the specific needs of people with autism can vary widely, 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 Innovation, Universities and Skills and the Department for Work and Pensions **(Figure 3)**. 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.

Availability of data to identify need and inform planning

1.9 The exact prevalence of autism is not known, although it is estimated that there are around 400,000 adults with autism in England (approximately one per cent of the population) with around 50 per cent of this group being 'high-functioning'.[12]

1.10 At local level, Local Authorities and NHS organisations often lack robust data on numbers of adults with autism in their area, thus limiting their ability to identify need, plan capacity and commission appropriate services. Most Local Authorities responding to our survey struggled to interrogate their data systems to identify individuals with autism receiving services. Unless organisations had already established autism as a focus for service development, they did not record it as a separate diagnostic field. Only 18 per cent of Local Authorities and NHS partners who responded were able to give precise numbers of adults with low-functioning autism receiving services, with 48 per cent estimating figures. Only 12 per cent could do so for the high-functioning group, with a further 35 per cent estimating figures for this group. The few areas with a specialised service for people with high-functioning autism/Asperger Syndrome were generally able to provide better data on this group.

> **'Data from Children's Services increasingly records numbers of young people with ASD, but ASD is not listed as a client category within the Department of Adult Social Services […] We are not confident that all people who may have ASD are recognised and recorded as having ASD.'**
>
> *Local Authority Survey Respondent (Source: NAO)*

1.11 One further source of data which could assist local health and social care organisations to estimate need more accurately is GP records. However, only one in five GPs reported that they kept registers of patients with autism; only 12 per cent said they kept registers of all patients with autism; six per cent kept registers of patients with high-functioning autism, and two per cent registered patients with low-functioning autism.

Key strategies and service plans relevant to autism services

1.12 Adult social care services are currently being reconfigured to implement the reforms outlined in *Our health, our care, our say*[13] and *Putting people first.*[14] In addition to a new focus on preventive services (below, paragraph 3.10) and personalisation (below, paragraph 3.44), the reforms also emphasise the need for joined-up strategies and services. Effective joining up is essential to meeting the needs of people with autism, who require concerted support across a wide range of local organisations, including health and social care, housing, education and employment services.

1.13 The Joint Strategic Needs Assessment (JSNA) is intended to 'identify current and future health and wellbeing needs in light of existing services, and inform future service planning taking into account evidence of effectiveness.'[15] It informs joined-up strategic planning by Local Authorities and their partner organisations. 92 per cent of Local Authorities responding to our survey report that they have a JSNA in place, but only 21 per cent of these say that it includes specific information on the needs of people with autism. Thirty-three per cent said they planned to include specific information on the needs of people with autism in future. A recent joint review by the Commission for Social Care Inspection, Healthcare Commission and Mental Health Act Commission also found that local JSNAs were currently weak in their coverage of learning disabilities and complex needs, both of which would include people with low-functioning autism.[16]

---

[12] Knapp et al., *The Economic Consequences of Autism in the UK* (2007).

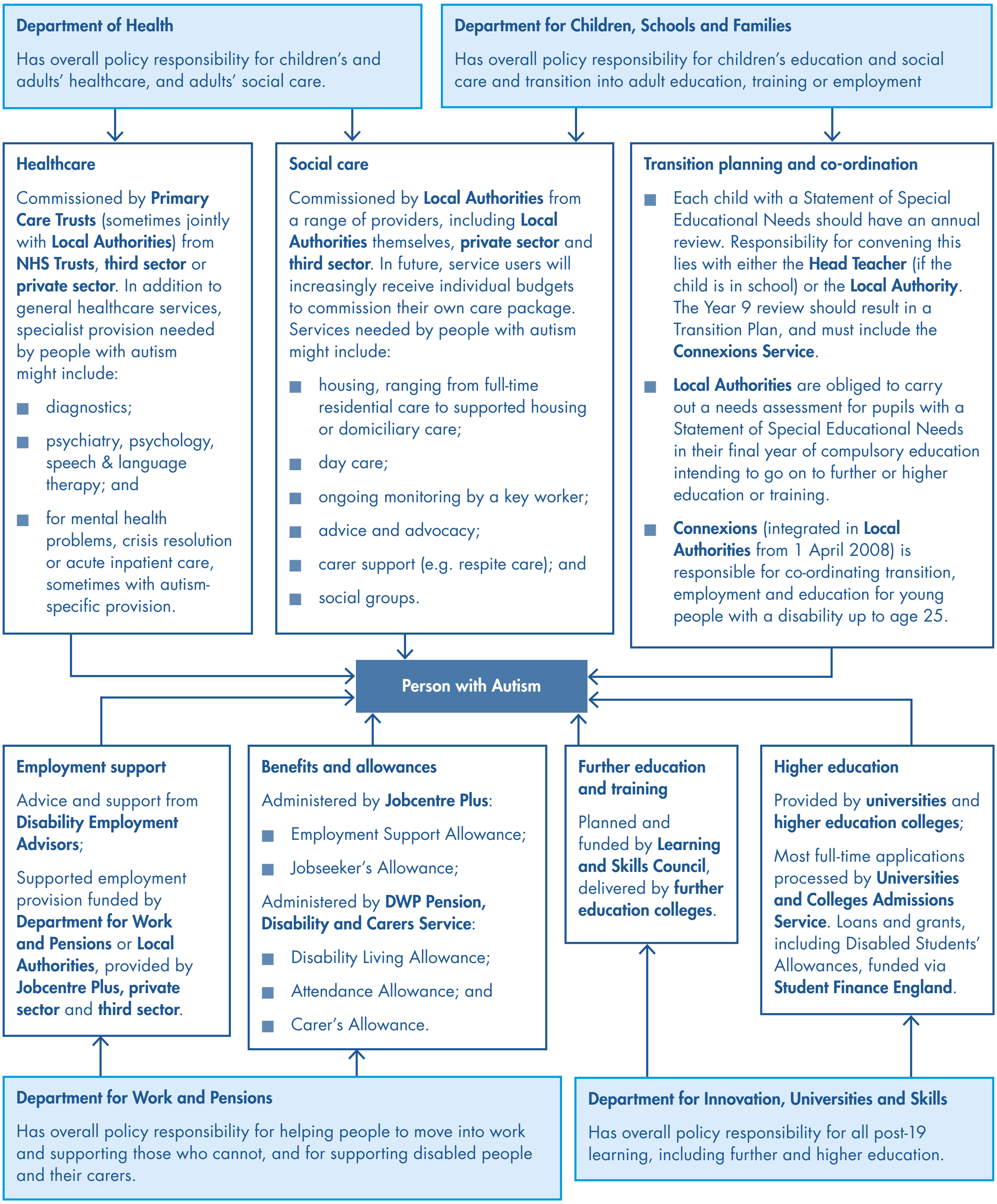
[13] Department of Health, *Our health, our care, our say – a new direction for community services* (30 January 2006) (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453).

[14] Department of Health et al., *Putting people first: a shared vision and commitment to the transformation of adult social care* (10 December 2007).

[15] Department of Health, *Guidance on Joint Strategic Needs Assessment* (13 December 2007), p. 7 (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081097).

[16] Commission for Social Care Inspection, Healthcare Commission and Mental Health Act Commission, *Commissioning services and support for people with learning disabilities and complex needs: National report of joint review* (March 2009), p. 24. (http://www.healthcarecommission.org.uk/_db/_documents/Report_for_commissioning_LD_joint_review.pdf).

3 Main Government departments responsible for provision of services to people with autism



Department of Health

Has overall policy responsibility for children's and adults' healthcare, and adults' social care.

Department for Children, Schools and Families

Has overall policy responsibility for children's education and social care and transition into adult education, training or employment

Healthcare

Commissioned by **Primary Care Trusts** (sometimes jointly with **Local Authorities**) from **NHS Trusts**, **third sector** or **private sector**. In addition to general healthcare services, specialist provision needed by people with autism might include:

- diagnostics;
- psychiatry, psychology, speech & language therapy; and
- for mental health problems, crisis resolution or acute inpatient care, sometimes with autism-specific provision.

Social care

Commissioned by **Local Authorities** from a range of providers, including **Local Authorities** themselves, **private sector** and **third sector**. In future, service users will increasingly receive individual budgets to commission their own care package. Services needed by people with autism might include:

- housing, ranging from full-time residential care to supported housing or domiciliary care;
- day care;
- ongoing monitoring by a key worker;
- advice and advocacy;
- carer support (e.g. respite care); and
- social groups.

Transition planning and co-ordination

- Each child with a Statement of Special Educational Needs should have an annual review. Responsibility for convening this lies with either the **Head Teacher** (if the child is in school) or the **Local Authority**. The Year 9 review should result in a Transition Plan, and must include the **Connexions Service**.
- **Local Authorities** are obliged to carry out a needs assessment for pupils with a Statement of Special Educational Needs in their final year of compulsory education intending to go on to further or higher education or training.
- **Connexions** (integrated in **Local Authorities** from 1 April 2008) is responsible for co-ordinating transition, employment and education for young people with a disability up to age 25.

Person with Autism

Employment support

Advice and support from **Disability Employment Advisors**;

Supported employment provision funded by **Department for Work and Pensions** or **Local Authorities**, provided by **Jobcentre Plus, private sector** and **third sector**.

Benefits and allowances

Administered by **Jobcentre Plus**:

- Employment Support Allowance;
- Jobseeker's Allowance;

Administered by **DWP Pension, Disability and Carers Service**:

- Disability Living Allowance;
- Attendance Allowance; and
- Carer's Allowance.

Further education and training

Planned and funded by **Learning and Skills Council**, delivered by **further education colleges**.

Higher education

Provided by **universities** and **higher education colleges**;

Most full-time applications processed by **Universities and Colleges Admissions Service**. Loans and grants, including Disabled Students' Allowances, funded via **Student Finance England**.

Department for Work and Pensions

Has overall policy responsibility for helping people to move into work and supporting those who cannot, and for supporting disabled people and their carers.

Department for Innovation, Universities and Skills

Has overall policy responsibility for all post-19 learning, including further and higher education.

Source: National Audit Office

NOTE

Although this report focuses on the role of these four key departments in providing services, a number of other departments have policy responsibilities which may be relevant to people with autism. 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.

1.14 A further national policy relevant to the needs of people with autism is the Department for Communities and Local Government's *Supporting People* programme, which is designed to offer vulnerable people a stable environment to improve their quality of life, particularly through the provision of 'high-quality and strategically planned housing-related services'.[17] People with autism often have specific sensory and environmental requirements,[18] and hence appropriate specialised housing can be important in maintaining their independence and well-being. Yet only 22 per cent of respondents to our survey of Local Authorities said that their *Supporting People* strategy specifically addressed the needs of adults with autism.

1.15 Department of Health guidance states that the Director of Adult Social Services in each Local Authority 'should ensure that it is clear which team, or manager, within his or her staff, has responsibility for assessing and meeting the eligible needs of a range of named client groups',[19] of which autism is one. While only four per cent of Local Authorities reported that they do not have a named lead service for adults with 'low-functioning' autism, this proportion rose to 31 per cent for adults with 'high-functioning' autism.[20]

1.16 Our survey also showed that most local organisations do not have a specific commissioning strategy for adults with autism. Seventy-four per cent of Local Authorities responding to our survey said they and their NHS partners did not have such a strategy, and only 50 per cent reported having a strategic planning group dealing with the needs of adults with autism. Of those which did have a group, 87 per cent had input from multiple agencies. The organisations represented were Local Authority Social Services teams, both Children's and Adult services; Education services; Primary Care and Mental Health Trust representatives; and Learning Disability Partnership Boards. Fifty-seven per cent mentioned input from commissioners, 66 per cent include both Local Authority and NHS input, and 43 per cent include some input from service users or carers, usually through Learning Disability Partnership Boards.

Transition from childhood to adult services

1.17 In areas with a lack of appropriate services for adults with autism (particularly those with high-functioning autism or Asperger Syndrome), the move from children's services can be difficult. Even where services exist to meet the needs of adults with autism, access to these will depend partly on an effective transition process, with joint planning and information sharing between health, social care, education and employment services.

1.18 Diagnosis, monitoring and awareness of autism in children have improved rapidly in recent years, so identification rates are higher for this group than for adults. In principle, children with autism should therefore be known to services, and should benefit from a planned and tailored transition from education into adult life. By identifying and recording young people with autism moving up through the system, Local Authorities should also be better placed to analyse future need and plan future provision of adult services for this group.

1.19 However, many Local Authorities were unable to provide basic information on the Special Educational Needs and transition arrangements for children with autism in their area. Data on children with autism who have a Statement of Special Educational Needs or are at School Action Plus (i.e. with a Special Educational Need but no Statement) is collected routinely as part of the Schools Census, but 21 per cent of Local Authorities responding to our survey reported that they did not know how many such children were living in their local area. Twenty-one per cent did not know how many children aged 14-16 fell into this group. Only 45 per cent of Local Authorities said they knew how many children with autism with a Statement of Special Educational Needs had a completed transition plan. Only 29 per cent knew for how many a plan was being compiled.

---

[17] Introduction to *Supporting People* at http://www.spkweb.org.uk. See also Department for Communities and Local Government, *Independence and Opportunity – Our Strategy for Supporting People* (June 2007). (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134801).

[18] See, for example, Powell A, *Taking Responsibility: Good practice guidelines for services – Adults with Asperger syndrome* (National Autistic Society, 2002), pp. 65f.

[19] Department of Health, *Best Practice Guidance on the Role of the Director of Adult Social Services* (15 May 2006), pp. 20f. (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134801).

[20] Autism is not a mental illness, although people with autism can also develop mental health problems (at which point they will often access mainstream mental health services), and hence our survey asked: 'Which service has lead responsibility for adults with Autistic Spectrum Disorder who do not have an identified mental health problem?'

1.20 There is research suggesting that in the past, transition planning for young people with Special Educational Needs (including autism) has been generally poor.[21] One study of young people with Special Educational Needs found that less than half of those taking part could recall attending a transition planning review,[22] while research carried out in 2001 found that only 53 per cent of young people with autism who should have had a transition plan actually had some form of plan in place. Only 16 per cent had their identified needs met in full.[23]

> **'After leaving school, no real support […] No agency speaks to each other.'**
>
> *Adult with autism (Source: NAO web consultation)*

1.21 In our interviews and focus groups with transition managers and employment support providers, a recurring theme was that transition support required more effective leadership and relationships between services, including employment support. Participants felt that there was confusion around who was the lead, and whether individuals were covered by children's or adult services. They also felt there was a lack of clarity about the roles of health, education, and social services, often resulting in the absence of a decision-making authority, conflicts in responsibility, and lack of understanding between services. A survey of parents of autistic children in 2006 showed that only one quarter felt that transition support was coordinated.[24]

1.22 The Department of Health and the Department for Children, Schools and Families have acknowledged that more needs to be done to co-ordinate services for disabled young people in transition, and in 2007 and 2008 issued joint guidance for local services on roles, responsibilities and good practice.[25] The Departments are also running a £19 million Transition Support Programme,[26] which will seek to raise the standards of transition support and achieve greater consistency in all local areas. The programme consists of two main elements:

- a National Transition Support team, which will coordinate the work with Local Authorities, Primary Care Trusts and regional advisers and existing experts; and
- support for change at local level through a combination of direct grants and regional adviser activity.

1.23 This programme provides an opportunity for the Department for Children, Schools and Families to assess and improve Local Authorities' compliance with the Special Educational Needs code of practice[27] requirement to have early and effective transition planning in place for young people with autism.

Connexions' support for young people with autism

1.24 Connexions is a Government-funded service which through multi-agency working aims to provide young people with information, advice and guidance, including on careers. It is intended to give them access to personal development opportunities to help remove barriers to learning and progression, and ensure they make a smooth transition to adulthood and working life. Connexions is designed to help all young people aged 13-19 regardless of need, and those aged up to 25 with a learning difficulty or disability.

1.25 The Department for Children, Schools and Families has a Public Service Agreement (PSA) target to reduce the proportion of 16-18 year olds not in education, employment or training (NEET) by two percentage points by 2010, from a baseline of 9.6 per cent at the end of 2004. It therefore collects information from local Connexions providers on the numbers of 16-18 year olds who are NEET, to help manage performance against the target.

---

[21] Dee. L, *Improving Transition Planning - Helping Young People with Special Educational Needs* (Open University Press, 2006).

[22] Institute for Employment Studies, *Post-16 Transitions: A Longitudinal Study of Young People with Special Educational Needs: Wave Two* (Department for Education and Skills, 2004). (http://www.employment-studies.co.uk/pdflibrary/rr582.pdf).

[23] National Autistic Society, *Ignored or ineligible: The reality for adults with autism spectrum disorders* (2001), p. 12 (http://www.autism.org.uk/content/1/c4/28/61/ignored.pdf).

[24] National Autistic Society, *Moving on up? Negotiating the transition to adulthood for young people with autism* (2006), p. 3 (http://www.autism.org.uk/content/1/c6/01/39/64/Moving%20on%20up%20%28England%29.pdf).

[25] Department for Children, Schools and Families/Department of Health, *A transition guide for all services – key information for professionals about the transition process for disabled young people* (2007) and Department for Children, Schools and Families/Department of Health, *Transition: moving on well – A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability* (February 2008).

[26] http://www.transitionsupportprogramme.org.uk/default.aspx.

[27] Department for Education and Skills, *Special Educational Needs Code of Practice* (November 2001), chapter 9 (http://www.teachernet.gov.uk/_doc/3724/SENCodeOfPractice.pdf).

1.26 The Department also benchmarks Local Authorities regarding the proportion of 16-19 year-olds with learning difficulties or disabilities who are NEET, but does not do so past the age of 19. There is a risk, therefore, that Connexions is losing sight of its 19-25 client group, even if these clients have not made the transition to alternative support. As at December 2008, Connexions did not know the training, employment or education status of 31 per cent of its clients aged 16-24 with a learning difficulty or disability. A recent longitudinal study of young people with Special Educational Needs found that only a fifth could recall seeing a Connexions Personal Advisor or a careers service advisor since the previous phase of the study, during which time they had passed age 19,[28] and almost a quarter (22 per cent) said that they had not had contact with any professional support services during that period.[29]

1.27 Until 2008, Section 140 of the Learning and Skills Act (2000) required all pupils with a Statement of Special Educational Needs who were expected to go on to further or higher education or training to have a needs assessment (a 'Section 140 assessment'), to be carried out by Connexions in the final year of compulsory education. The Education and Skills Act (2008) transferred this responsibility from Connexions to Local Authorities, as well as giving them the power to arrange assessments for people with a learning difficulty but no Statement who are in their last year of compulsory schooling, or are over compulsory school age but under 25, and are receiving, or are likely to receive, post-16 education or training.

1.28 In our surveys of further and higher education institutions, we asked disability support officers for their comments on Section 140 assessments. Two thirds of respondents from further education institutions indicated that they found Section 140 assessments fairly useful, and 17 per cent said they were very useful. Nevertheless, half of the 50 respondents from further education colleges who provided more detailed comments felt that Section 140 assessments were vague or poor in quality, and while they were useful to highlight that the student had support needs, they did not provide sufficient details of what support was required.

> **'Section 140 assessments in general are useful. However, they are fraught with problems, as they are not standard throughout Connexions as an organisation […] Connexions should make more effort to provide historical information, especially Statements of Educational Need, Educational Psychologists' reports, medical history on the condition, etc, as this would help the learners when moving into further education.'**
>
> *Further Education Disability Support Officer*
> *(Source: NAO survey)*

1.29 For higher education institutions there was much less contact with Connexions, with 56 per cent of respondents to our survey saying they never received Section 140 assessments from the Connexions service; 26 per cent saying they received them in some cases; 18 per cent in most cases, and no respondents receiving them in all cases.

---

[28] Institute for Employment Studies, *Post-16 Transitions: A Longitudinal Study of Young People with Special Educational Needs: Wave Three* (Department for Education and Skills, 2005), p. 53 (http://www.employment-studies.co.uk/pdflibrary/rr655.pdf).

[29] Ibid.

PART TWO

Knowledge and awareness of autism across public services

Understanding and awareness of autism amongst health and social care professionals

2.1 For adults with autism (both diagnosed and undiagnosed), GPs may well be their first point of contact with healthcare services. We asked GPs to estimate the number of patients they saw over a typical six-month period whom they suspected of having undiagnosed autism. The median estimates were that GPs typically see 1,500 adults aged between 18 and 65, of whom two have suspected undiagnosed autism (both high-functioning), and 800 older people (aged 65 and over) of whom none have suspected undiagnosed autism. If each GP in England did, indeed, see about two adults with undiagnosed high-functioning autism every six months, this would suggest that up to 120,000 adult patients are presenting with suspected undiagnosed high-functioning autism each year.

2.2 While these figures are clearly estimates and need to be treated with caution, they do confirm that, although GPs may not themselves have the specialist skills to diagnose autism (see below, Part 3), they do need to be able to identify adults requiring a diagnostic assessment, and make an appropriate referral. They also need to take the lead in managing the ongoing health needs of people with autism, particularly if other specialised support services are not available locally.

2.3 Eighty per cent of GPs responding to our survey felt that they required additional guidance and training to identify and manage patients with autism more effectively. In particular, they mentioned the need for guidance on how to identify possible autism, what referral protocols should be in place (particularly for adults with suspected high-functioning autism), and what services are, or should be, available locally. Commonly suggested ways to address this need included e-training modules, a NICE clinical guideline, and half-day or full-day training courses from experts in diagnosis and management of autism.

> **'After seeing an educational psychologist I was told to see my GP. My GP said I couldn't have Asperger's Syndrome as I was talking...!'**
>
> *Adult with autism (Source: NAO web consultation)*

2.4 More widely, there is scope to improve the level of autism-specific training provided to health and social care staff across the country. According to our survey, 24 per cent of local training plans for NHS staff, and 23 per cent of training plans for social care staff, do not address specifically the needs of adults with autism, and one in ten respondents explicitly mentioned training and awareness as a reason why adults with autism found it difficult to access services.

2.5 Training and awareness of the specific challenges faced by people with autism is particularly important when assessing their needs, and hence their eligibility for care services and carer support. People with Asperger Syndrome and high-functioning autism can appear articulate and able at first sight, yet still require considerable support to cope with aspects of day-to-day life such as personal care and transport. Only 30 per cent of Local Authorities responding to our survey said that training for their staff carrying out needs assessments under Fair Access to Care Services covered high-functioning autism and the needs of people who have it. Recent work by the Commission for Social Care Inspection also found that assessments of needs are often inadequate, and highlighted people with autism as a group that are neglected in the needs-assessment process.[30]

---

[30] Commission for Social Care Inspection, *Cutting the cake fairly: CSCI review of eligibility criteria for social care* (October 2008), p.4 (http://www.csci.org.uk/pdf/FACS_2008_03.pdf).

2.6 Our interviews and focus groups also suggested that there was a lack of knowledge of autism among staff working in local services, particularly those involved in transition. Many people suggested that more training in autism was required for key workers such as employment advisors, social workers and teachers. The importance of appropriate training for Connexions Personal Advisors was also commented on by respondents to our surveys of further and higher education institutions. A student support coordinator at a further education college, for example, said that 'the usefulness of the Connexions Section 140 assessments very much depends on the individual Personal Advisor. Many do not have specialist training in working with learners with learning difficulties or disabilities.' A 2006 survey of parents echoed this view, with one in three parents reporting that they felt Connexions' knowledge of autism to be inadequate.[31]

Understanding and awareness of autism in the benefits system

2.7 People with autism and their carers report a range of experiences of autism awareness within the benefits system. While some felt that assessors for benefits such as Incapacity Benefit and Disability Living Allowance demonstrated a good understanding of autism, others reported that assessors knew little about the condition and had consequently not recognised the extent of their needs.

2.8 Department for Work and Pensions decision-makers draw on evidence from a number of sources when assessing an applicant's entitlement to benefits. These can include a statement from the applicant's GP, an examination by a healthcare professional from the Department's Medical Services provider Atos, and additional evidence from carers and health and social care professionals. Low awareness and knowledge of autism amongst GPs and health and social care staff (above, paragraph 2.3) mean that the evidence they provide to decision makers regarding the needs of applicants with autism is likely to be of variable quality. It is important, therefore, that Medical Services healthcare professionals involved in benefit assessments have knowledge and awareness of autism, and that decision makers make full use of their input to ensure that applicants' needs are fully recognised.

2.9 Assessing the extent to which the needs of people with autism are being recognised by benefits assessors and decision makers, for example by analysing whether the proportion of eligibility decisions later overturned at appeal differs significantly between autistic people and other groups, has not been possible to date owing to lack of data (below, paragraph 3.36). From October 2008, however, the Department has been recording whether applicants for Disability Living Allowance have a diagnosis of autism, and hence it will be possible in future to explore the quality of needs assessment and decision-making for this group in more detail.

Understanding and awareness of autism in Jobcentre Plus services

2.10 There is also scope to improve knowledge of autism among Jobcentre Plus Disability Employment Advisors, whose role is to provide specialised support on employment issues for disabled people who are either in work or looking for a job. Prior to November 2005, the Department did not have an integrated strategy for providing training to Disability Employment Advisors, which led to a shortfall in up-to-date knowledge of specific disabilities.[32] A more recent evaluation of Disability Employment Advisors also identified a lack of appropriate ongoing learning and development for those who have been in post for some time.[33]

2.11 Since November 2005, however, the Department has been including autism-specific content as part of its training for new Disability Employment Advisors. The Department reports that, of around 500 full-time equivalent Disability Employment Advisors in Great Britain (England-only figures are not available), 275 have completed the updated training.

2.12 Participants in our interviews, focus groups and web consultation reported that they had found Disability Employment Advisors with specialised autism knowledge an important source of help and support, but also confirmed that not all Disability Employment Advisors working with autistic people appeared to have received such training. Many respondents felt that lack of awareness of autism had led to inappropriate provision, and that advisors did not always signpost appropriately, collect or share appropriate information or correctly identify the needs associated with their condition.

---

[31] National Autistic Society, *Moving on up? Negotiating the transition to adulthood for young people with autism* (2006), p. 3 (http://www.autism.org.uk/content/1/c6/01/39/64/Moving%20on%20up%20%28England%29.pdf).

[32] See National Audit Office, *Gaining and retaining a job: the Department for Work and Pensions' support for disabled people* (HC: 455 2005-2006), p. 36 (http://www.nao.org.uk/publications/0506/gaining_and_retaining_a_job.aspx).

[33] *Department for Work and Pensions Research Report No 539: Disability Employment Adviser (DEA) Organisation in Jobcentre Plus* (2008), p. 40 (http://www dwp.gov.uk/asd/asd5/rports2007-2008/rrep539.pdf).

'I found out about the Disability Employment Adviser at the Job Centre, and took him [our son] along to her. However, this in itself brought further problems. She saw a very confident, capable and personable young man who should have no difficulty in getting a job! […] Eventually, nurturing her, it was concluded that he should be on Incapacity Benefit. […] Meanwhile, we persuaded the DEA to refer our son to the NAS Prospects programme. She knew nothing about the programme until we told her.'

Parent of an adult with high-functioning autism
(Source: NAO web consultation)

2.13 The Disability Employment Advisors and Personal Advisors we interviewed often felt that lack of autism knowledge was not a problem, because their role was more to signpost individuals to expert organisations. People with autism and their carers nevertheless reported that poor autism awareness amongst Disability Employment Advisors had a direct impact on the services they received, for example through failure to communicate effectively with them to identify support needs. A number of Disability Employment Advisors had acknowledged gaps in their knowledge of autism, and worked directly with a specialist autism charity to improve this knowledge and create appropriate service plans.

2.14 A number of respondents suggested that the introduction of Employment and Support Allowance and Work Capability Assessments (which have now replaced Incapacity Benefit and Personal Capability Assessments) could support more informed assessments of people with autism, because the Work Capability Assessment has been developed in consultation with the National Autistic Society, and now includes descriptors dealing with intellectual and cognitive function as well as physical disability.[34] Realising these potential benefits will depend partly on assessment staff provided by Medical Services (the organisation contracted to carry out Work Capability Assessments on behalf of the Department for Work and Pensions) having sufficient awareness and knowledge of autism.

Awareness of autism amongst employers and employees

2.15 Only 15 per cent of people with autism are in full-time employment,[35] despite the fact that many people with autism have valuable skills to offer prospective employers, for example attention to detail, concentration and mathematical aptitude. Some firms, such as BT **(Case Example 1 overleaf)**, have pro-actively recruited people with autism as part of their diversity policy, working with the National Autistic Society 'Prospects' service (see below, Part 4) to create an appropriate package of mentoring and reasonable adjustments[36] to support these staff.

2.16 To allow people with autism to fulfil their potential in the workplace, training and support are needed not just for the individuals concerned, but also for their employers and colleagues **(Case Example 2 overleaf)**. While two thirds of respondents in a recent study of public perceptions of autism stated that they would feel very or quite comfortable about working with someone with autism, only 17 per cent said they thought it would be a positive experience. Only 48 per cent had heard of Asperger Syndrome, and only 41 per cent of these were aware that it is a form of autism.[37] Our focus groups and interviews also suggested that people with autism found lack of understanding of autism amongst employers a significant barrier to work. People felt that working with employers was a crucial step to building understanding of disability and providing opportunities, and a number of autism specialists advocated the need for on-site employer and staff training when a person with autism starts work at an organisation.[38]

---

[34] See Department for Work and Pensions, *Technical Factsheet T14 – Work Capability Assessment* (December 2008) (http://www.dwp.gov.uk/esa/pdfs/t14-esa-factsheet-work-capability-assessment.pdf).

[35] 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%20acrt%20pos.pdf).

[36] The Disability Discrimination Act (DDA) 1995 makes it unlawful to discriminate against employees or job applicants on the grounds of disability. Employers are legally responsible for making 'reasonable adjustments' to recruitment processes, work arrangements and the working environment in order to accommodate disabled people.

[37] National Autistic Society, *Think Differently, Act Positively – Public Perceptions of Autism* (2008), p. 10 (http://www.autism.org.uk/content/1/c6/01/47/21/think%20diff%20acrt%20pos.pdf).

[38] See NAO accompanying report, *Benefits and employment support schemes to meet the needs of people with an Autistic Spectrum Disorder*, paragraphs 5.41f.

CASE EXAMPLE 1

Increased autism awareness can help employers recruit and retain staff

As part of its diversity policy, BT has worked closely with the National Autistic Society to understand precisely what skills people with autism are likely to possess and identify jobs where these would be a particular advantage. These generally fall into two categories:

1) Administrative roles requiring repetition and great accuracy, for example 'logistical picking';

2) Higher-functioning IT-related roles, for example working with large volumes of complex data, sometimes under great time pressure, or identifying creative applications for new technologies.

When recruiting people with autism, BT has learned to use more flexible and innovative methods to identify and assess candidates – for example asking less open questions, eliminating the use of hypothetical situations, encouraging the presence of support workers at interviews and using 'work trials' where specific aptitudes are more relevant than inter-personal skills.

The adjustments required for people with autism (such as changes to the environment to minimise sensory overload) have proved relatively straightforward and inexpensive. All BT employees have access to a named mentor, and for staff with autism this arrangement is supplemented by specialised support from the NAS Prospects service.

Information on autism, aimed at both people with autism and their colleagues, is available on the company intranet. There are also on-line fora for people with disabilities (including autism), allowing staff to support each other and share experiences and advice on issues such as promotion. Such fora can be particularly helpful for 'myth-busting' and raising awareness amongst colleagues.

Each member of staff has the opportunity to create an 'employee passport', a document which records very specifically their particular needs and possible 'trigger factors' for any health or well-being-related problems. As the passport always transfers with the individual from one manager to another, it supports continuity whilst allowing career mobility. This facility is particularly useful for people with autism, who can be sensitive to changes in their routine and environment.

Source: National Audit Office/BT

CASE EXAMPLE 2

Training for colleagues and employers as part of employment support for people with autism

Yusef, a young man who has Asperger Syndrome, started the Work Preparation programme at Prospects in November 2007. Yusef has an inability to fully understand the social situation in which he finds himself, which can lead to him acting inappropriately or talking excessively about one subject. To find Yusef a job, a Prospects advisor worked with him to put strategies in place to improve his communication and concentration.

As a result of the programme with Prospects, Yusef secured employment within a major library as a stamping and labelling assistant.

Yusef's new colleagues also needed training in order for them to understand his way of working. This training included setting boundaries and rules for him in his work and during conversations. For example, his colleagues learned to tell him, pleasantly but clearly, when it was time to stop talking and get back to work.

The support that Yusef received was very effective. He has now settled down into his job, and his colleagues have reported that they have found the training to be beneficial for both him and them. Yusef is now an established member of the team, and with support from Prospects he is expected to continue to do well within the role.

Source: National Audit Office/National Autistic Society 'Prospects' Service

Eligibility and access to service

Service configuration and access to health and social care

3.1 Health and social care services in England have traditionally been configured to cater for people with a learning disability (usually defined as having an I.Q. less than 70), a physical illness or disability, or a mental health problem. Whilst people with so-called 'low-functioning' autism are likely to be eligible for learning disability services, the 'high-functioning' group (including people with Asperger Syndrome) are often excluded because they have an I.Q over 70. In the past, some Local Authorities have explicitly ruled out people with Asperger Syndrome from even being assessed for care services.[39]

3.2 Similarly, people with high-functioning autism struggle to access existing mental health services unless they have a diagnosable mental illness (which autism is not). They may therefore fall through a gap between learning disability and mental health services, only accessing the latter in the form of costly and acute interventions if they subsequently develop mental health problems, which may be brought on by depression and social isolation associated with their autism.

3.3 The Department of Health has stated in guidance to Local Authorities and NHS bodies that people with higher-functioning autism should not be precluded from accessing the services they require.[40] However, a recent review by the Commission for Social Care Inspection (CSCI) found that the current eligibility criteria and assessment processes had led to 'inadequate and unduly standardised assessments and neglect of […] people with Asperger Syndrome/autism, whose support needs are often not understood'.[41] In our own survey of Local Authorities and NHS bodies, 74 per cent of respondents said that adults with autism who do not meet eligibility criteria experience or report difficulties accessing the services they require.

3.4 The Government's Public Service Agreement (PSA) Target 16[42] aims to 'increase the proportion of socially excluded adults in settled accommodation and employment, education or training'. The groups explicitly targeted by the PSA include 'adults in contact with secondary mental health services' and 'adults with moderate to severe learning disabilities', both of which may include people with autism. Because of the differences in eligibility and access for people with 'high-functioning' autism, however, there is a risk that this target will not support their social inclusion in all parts of the country.

Diagnostic services

3.5 As part of the personalisation agenda in social care, the Department of Health aims to practice a 'social' rather than 'medical' model of disability, focusing on people's needs rather than diagnostic 'labels'. Therefore people do not necessarily require a medical diagnosis to be eligible for care services, and conversely having a diagnosis will not in itself mean automatic eligibility for support.

---

[39] See Department of Health, *Fair Access To Care Services Practice Guidance – Implementation Questions and Answers* (6 March 2003), p. 15: 'Some councils go further by declaring that they do not help particular groups of individuals, such as those with higher functioning autism/Asperger Syndrome, and make no attempt to assess needs as they should do.'

[40] See Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21st Century: Implementation Guidance* (HSC 2001/016: LAC (2001)23, (31 August 2001), p. 2; Department of Health, *Fair Access To Care Services Practice Guidance – Implementation Questions and Answers* (6 March 2003), p. 15, and Department of Health, *Better Services for Adults with Autism* (2007), p. 7.

[41] Commission for Social Care Inspection, *Cutting the cake fairly: CSCI review of eligibility criteria for social care* (October 2008), p. 37 (http://www.csci.org.uk/pdf/FACS_2008_03.pdf).

[42] 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).

3.6 This approach is supported by many people with a disability, who may also wish to focus on having their needs met rather than being 'labelled' with a medical diagnosis. In the case of autism, a diagnosis can nonetheless be helpful in informing assessments of a person's likely support needs, particularly as the extent of these needs may be partially hidden by a 'normal' I.Q. and language skills. Knowing that a person has a diagnosis of autism can be important in settings such as Jobcentre Plus, where Personal Advisors can access guidance on the needs of people with autism, but are unlikely to do so unless they are aware that their client has the condition. Many people with autism also report that a diagnosis has helped them make sense of difficulties experienced in their lives to date, for example with forming social relationships.

3.7 A diagnosis can also prevent people with autism being misdiagnosed with mental illness such as schizophrenia or depression, or coming into inappropriate contact with the criminal justice system.[43] Both these scenarios can have severe impacts on people's lives, as well as incurring high costs, for example through ongoing use of inappropriate medication or unnecessary confinement in secure accommodation.

3.8 Diagnosing autism requires considerable training and expertise, particularly in mental health settings where it may be difficult to distinguish from mental illness. Primary care clinicians such as GPs are generally not confident in identifying and diagnosing adults with autism, and hence specialised diagnostic services are required, ideally leading to a full multi-disciplinary assessment of the person's needs. Only 29 per cent of Local Authorities and NHS bodies responding to our survey reported having commissioned specialised autism diagnostic services in 2007-08. In our survey of GPs, 64 per cent told us that they referred adults with suspected high-functioning autism to adult mental health services, and 19 per cent to learning disability services. Twelve per cent were not sure where they should refer such patients, and only ten per cent reported that they would refer them to a specialised autism diagnostic service.[44]

'I recently had a chap with all the symptoms […] but failed to find anyone in the area to diagnose him.'

GP (Source: NAO survey)

Access to support services for adults with autism

3.9 With appropriate support, there is potential for people with autism to live relatively independently in the community, requiring low-intensity services such as monitoring by a trained caseworker. Without such support, there is an increased risk of social exclusion and health problems, particularly mental illness. People may then engage with services only when their health has deteriorated, when they require 'acute' interventions such as Crisis Resolution Home Treatment or psychiatric inpatient care. Beside the negative impact of such crises on a person's life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day.[45]

3.10 Department of Health guidance to Local Authorities emphasises the need to focus on early support rather than later crisis management, stating that 'Councils should make changes in their practice to take a longer term preventative view of individuals' needs and circumstances'.[46] The Government's current reforms of the social care system under the white paper *Our Health, Our Care, Our Say* also place greater emphasis on the importance of prevention.[47]

3.11 In our survey of Local Authorities and NHS bodies, almost two thirds of respondents felt that currently available services were limited for adults with autism, citing supported accommodation, supported employment, recreational and social activities, and general support services such as advice and advocacy.

'My local social services department does not provide any autism-specific services, so these services are not at all flexible to my needs…'

Adult with autism (Source: NAO web consultation)

---

[43] See Royal College of Psychiatrists, *Psychiatric services for adolescents and adults with Asperger syndrome and other autistic-spectrum disorders* (April 2006) and Department of Health, *Better Services for People with an Autistic Spectrum Disorder – A Note Clarifying Current Government Policy and Describing Good Practice* (16 November 2006), pp. 18ff.

[44] As respondents to this question could tick all categories that applied (for example to report a specialised diagnostic service led by adult mental health services), the responses across all categories do not sum to 100 per cent.

[45] Source: Curtis L, *Unit Costs of Health and Social Care* (Canterbury: Personal Social Services Research Unit, 2008).

[46] Department of Health, *Fair Access to Care Services – Guidance on Eligibility Criteria for Adult Social Care* (1 January 2003), p. 1 (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653).

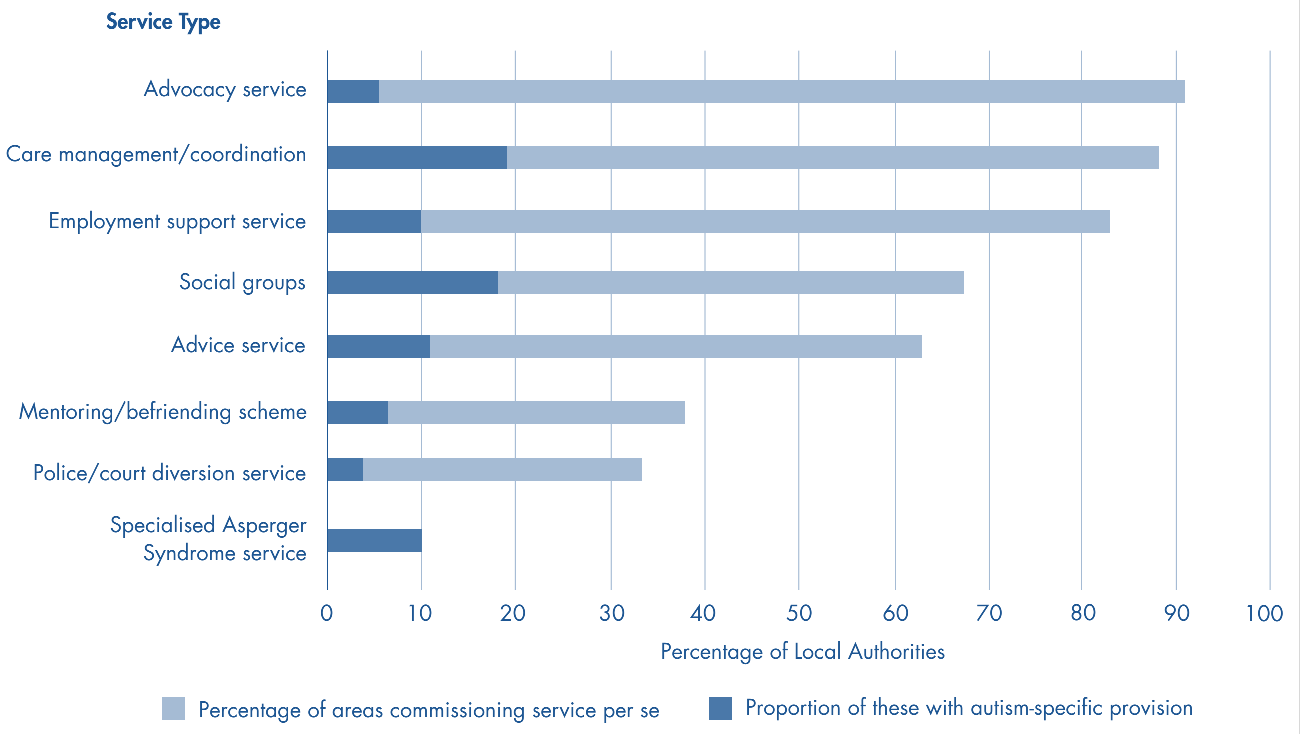
[47] Department of Health, *Our health, our care, our say – a new direction for community services* (30 January 2006), pp. 46ff. (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453).

3.12 Our survey showed that, while some generic preventative services (such as advocacy and care management/coordination) are being commissioned in the majority of areas, these rarely include specialised autism provision **(Figure 4)**. Only 19 per cent of respondent areas reported any specialised autism care management and co-ordination, only six per cent a mentoring/befriending service specifically for people with autism, and only five per cent a specialised advocacy service. Court diversion services, which aim to minimise the inappropriate entry of vulnerable adults into the criminal justice system, were reported in only 33 per cent of areas, and less than one in eight of these have specialised autism support. Only 10 per cent of areas have commissioned ongoing support from a specialist team for people with Asperger Syndrome.[48]

3.13 We also asked GPs how confident they were that people in their localities with both low- and high-functioning autism were receiving appropriate and adequate care for their needs. For both groups, 70 per cent of GPs said that they were either not at all, or not very, confident that appropriate and adequate care was being provided. Only 28 per cent of GPs were fairly confident, and only two per cent were very confident. Similarly, in our survey of third-sector autism service providers, 51 per cent of respondents felt that the way adult autism services are commissioned does not help to promote services meeting the needs of adults with autism.

3.14 In addition to the negative impacts on people with autism themselves, lack of diagnostic and support services also increase the burden placed on carers, particularly aging parents of adult children still living at home. Given that the services most successful at identifying individuals with high-functioning autism have only identified around 14 per cent of the estimated total in their area,[49] it is possible that large numbers of adults with autism are currently being supported solely by family carers. Apart from identifying and assessing the needs of these carers, Local Authorities also need to recognise that such arrangements will not be sustainable indefinitely, and that specialised provision will need to be in place to prevent a crisis once circumstances change and family carers are no longer able to cope.

4 Percentage of local authority areas with generic and autism-specific preventative services



Source: National Audit Office survey of Local Authorities and NHS partners

---

[48] This figure includes areas commissioning ongoing support through block and service level agreements, rather than those reporting spot commissioning, which could include one-off diagnostic assessments performed out of area but no general provision for their own population.

[49] Source: Analysis of NAO Local Authority/NHS survey data and discussion with specialist services. As in the economic model (Appendix 2), we have estimated the total number of adults with high-functioning autism as 0.5 per cent of the ONS population estimate (aged 16-59/64) for the area covered by the service. Details of the assumptions underpinning this estimate are included in the full paper describing the economic modelling, available on the NAO website (www.nao.org.uk).

Out-of-area placements

3.15 Variations in levels of local service provision mean that many Local Authorities and NHS bodies are commissioning residential and inpatient services out-of-area. 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), with sufficient investment in specialised settings and staff, some services could potentially be provided locally at lower cost.

3.16 In our survey of Local Authorities and NHS bodies, 53 per cent of all respondents reported that they were funding at least one adult out of area in a supported housing, residential or long-term inpatient mental health setting. A further 16 per cent stated they did not know how many adults they were funding out-of-area for any of the above services. People with autism often prefer routine, and find coping with change difficult, so it can be difficult to bring back service users from such long-term settings once they have been placed there.

3.17 Routine data on numbers and costs of people with autism in out-of-area placements is limited, particularly as specialised mental health provision for complex needs is often provided by the independent sector, and hence not captured by national datasets such as Hospital Episode Statistics and the Mental Health Minimum Dataset.[50]

3.18 In our survey of Local Authorities and NHS bodies, only 50 authorities could give us information on supported housing services commissioned for adults. Of those, 25 (50 per cent) commissioned at least some of these services out-of-area. The proportion of supported housing placements for adults that were provided out-of-area ranged from one per cent to 100 per cent, with an average of 30 per cent. Fifty-six authorities gave us figures on residential care. Forty-nine of these (88 per cent) commissioned some out-of-area care. The proportion of residential placements for adults that were provided out-of-area varied from 14 per cent to 100 per cent, with an average of 62 per cent. 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.

3.19 Although national data on out-of-area placements are limited, a systematic review of existing research on placements for people with learning difficulties (including people with autism) was conducted for the Social Care Institute for Excellence in 2008.[51] It concluded that the evidence base on this topic is relatively small, but that the financial cost to authorities funding out-of-area placements can be high. For example, Calderdale Council examined out-of-area placements in 2007, and found that the average weekly cost of a placement for autism was over £1,900 (£101,000 per annum).[52] Where comparative data are available, out-of-area placements are on average more expensive than locally based services **(Box 2)**.

3.20 The main groups to be placed out-of-area were those with challenging behaviour, autism, mental health needs, complex health needs and forensic needs. Those placed were more likely to be male, consistent with a greater prevalence of autism and challenging behaviour among men than women. Out-of-area placements were made for predominantly negative reasons, such as dissatisfaction with or unavailability of local services, rather than for positive reasons such as being nearer to family or meeting cultural preferences.

BOX 2

Comparative costs of out-of-area placements in England

- A study of high-cost (over £70,000 per annum) services for people with learning difficulties and challenging behaviour in five London boroughs in 2006 found that the mean cost of out-of-borough placements was £106,000 (range £70,000 to £258,000), compared with a mean cost for in-borough placements of £98,000 (range £70,000 to £195,000).
- A 2006 study in the West Midlands found that the average annual cost for those with complex mental health needs placed out-of-area was £98,000, compared with an average in-area cost of £75,000. The average out-of-area cost for those with severe learning disabilities was £47,000, compared with an average in-area cost of £43,000.

Source: Emerson and Robertson, Commissioning person-centred, cost-effective, local support for people with learning difficulties (2008)

---

[50] See Glossary for definitions of these datasets. The independent sector is not currently mandated to provide data for the MHMDS, although from April 2009 a subset of the MHMDS is also required from commissioned independent Mental Health care providers.

[51] Emerson E and Robertson J, *Commissioning person-centred, cost-effective, local support for people with learning difficulties* (Social Care Institute for Excellence, July 2008) (http://www.scie.org.uk/publications/knowledgereviews/kr20.pdf). See Glossary for details of the role and status of the Social Care Institute for Excellence.

[52] Ibid.

3.21 There have been no direct comparisons of the quality of out-of-area and locally based services, although there is evidence of shortcomings in the quality of some out-of-area placements, such as: lack of person-centred plans or health action plans; low levels of access to psychology, psychiatry and appropriate behavioural support for people with challenging behaviour; and lack of engagement in home and community activities.

3.22 The review concluded that the use of expensive out-of-area placements has a negative impact on local investment,[53] contributing to a situation where the lack of local services leads to further expenditure on out-of-area provision, removing resources which could be used to develop better services locally.

3.23 In our survey of Local Authorities and NHS bodies, 65 per cent of respondents said that they found it fairly difficult or very difficult to find appropriate supported housing for people with autism within area **(Figure 5 overleaf)**, and 68 per cent that they found it fairly difficult or very difficult to identify appropriate residential placements within area **(Figure 6 on page 29)**.

Enrolment, retention and achievement by young people and adults with autism in education

3.24 Young people and adults with autism can find many aspects of further and higher education challenging, for example coping with the social and physical environment and managing their time.[54] They may not achieve their full potential and complete their course, particularly if teaching and support staff lack specific knowledge and training in autism[55] (see Part 2).

3.25 The Learning and Skills Council has not previously collected autism-specific data on enrolment, retention and achievement for learners with autism in the further education system, making large-scale analysis of these issues difficult. From the 2008-09 academic year, however, both autism and Asperger Syndrome have been included as fields within the relevant national dataset, the Individualised Learner Record.[56] The resultant data should allow more detailed analysis of the extent to which current further education provision is meeting the needs of people with autism.

3.26 Available data on students with autism in higher education is less limited, although the numbers of students involved are relatively small and there is no obligation for them to declare their autism as a disability. The Universities and Colleges Admissions Service (UCAS) collates figures on the number of applicants to higher education institutions who declare that they have autism, and the Higher Education Statistics Agency (HESA) records the numbers of students on higher education courses with declared autism.

3.27 The relatively low numbers of students with autism in higher education, and the lack of national data on the prevalence of autism among students in further education, makes it difficult to carry out robust comparative analyses of educational outcomes of adults with autism. We therefore obtained evidence through a survey of disability support officers in further and higher education institutions, asking for comments on retention, success and achievement rates of students with autism.

3.28 The majority of respondents felt that, provided appropriate support was in place, retention and success rates for students identified with autism in further education should be good, and indeed that in many institutions they were. Of the 71 respondents from further education colleges who commented on retention and achievement rates for students with autism, 40 (56 per cent) said that these were good or excellent in their institutions. Only one respondent said that retention and achievement rates for students with autism were less than college and national averages, and three respondents said that rates were variable or moderate.

3.29 Respondents felt that retention, completion and success rates of students with autism in further education could be the same or better than other learners if they were provided with appropriate individualised support. Amongst the elements of such support mentioned were: personalised programmes; time-out and self-study areas; mentoring and advocacy; autism-specific teaching methods and materials, and participative approaches to learning. Similar views were expressed by respondents from higher education institutions. Respondents felt that with mentoring or one-to-one support (which may be financed via Disabled Students' Allowances), students with autism can generally complete their courses with good results.

---

[53] Emerson and Robertson, p 22.

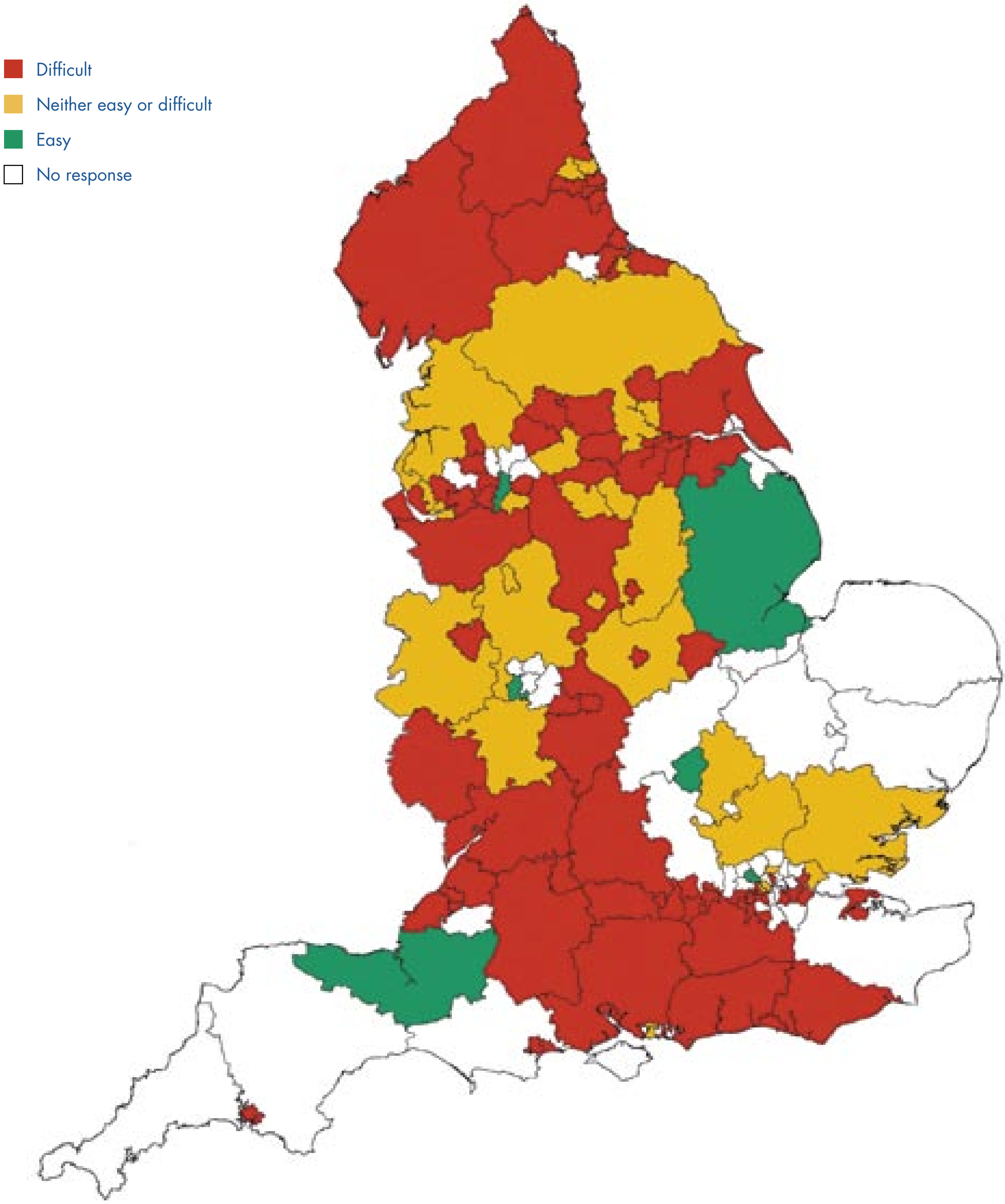
[54] See Breakey C, *The Autism Spectrum and Further Education: A Guide to Good Practice* (London: Jessica Kingsley Publishers, 2006), pp. 122-154.

[55] See, for example, Beardon L and Edmonds G, *The ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, pp. 150ff. (http://www.aspectaction.org.uk/).

[56] 'Autistic Spectrum Disorder' will be included as a category in Field L16 ('Learning Difficulty'), and Asperger Syndrome in Field L15 ('Disability'). Source: *The Information Authority, Specification of the Individualised Learner Record for 2008/09 – Version 3.0* (August 2008) (http://www.theia.org.uk/NR/rdonlyres/B6A83D9A-A1C2-4AA0-A633-DE45A116CD16/0/natILRSpecification2008_09v318Aug2008.pdf).

5 Relative difficulty of finding appropriate supported housing locally to meet the needs of people with autism

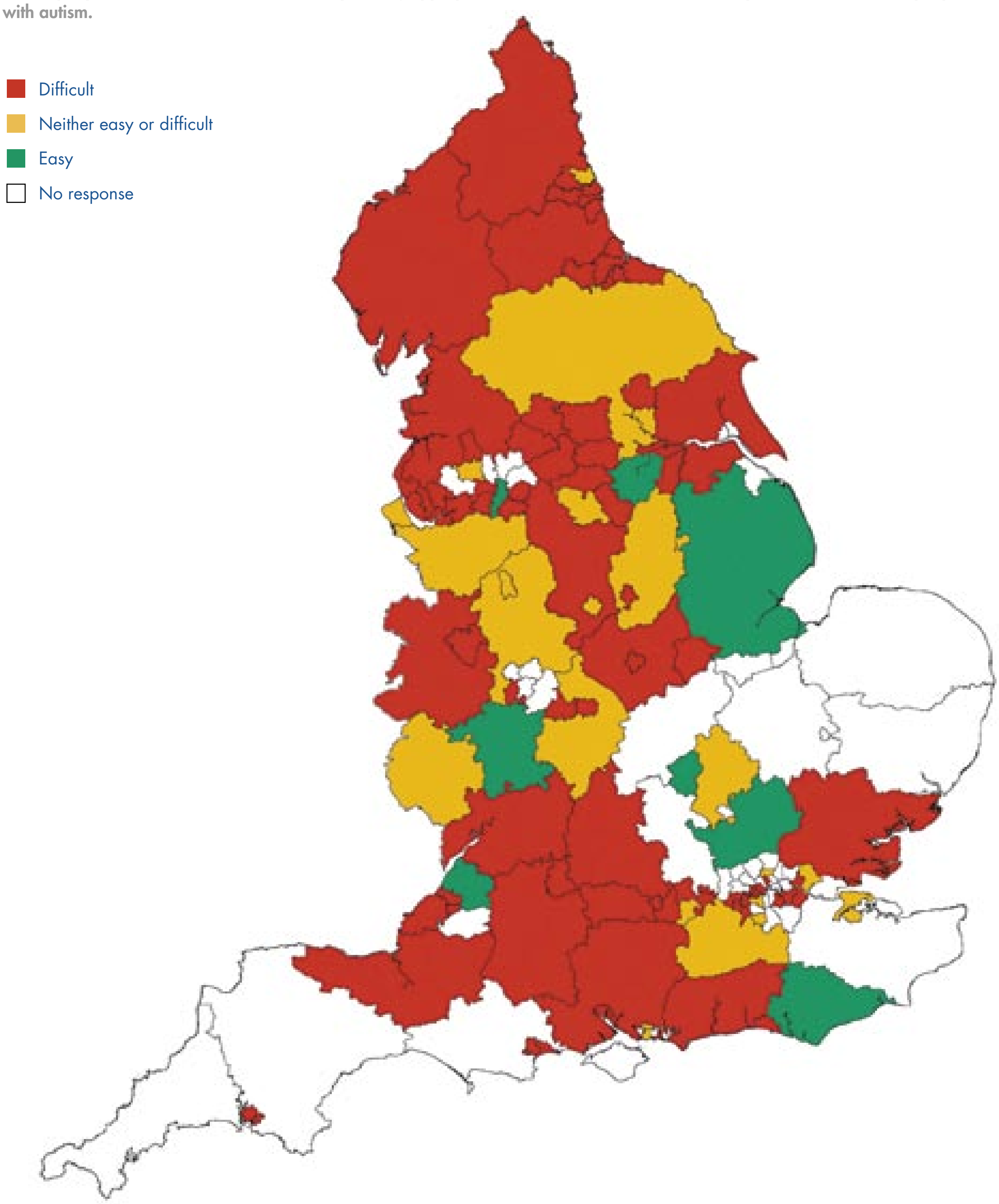
The majority of Local Authorities have difficulty finding appropriate supported housing locally to meet the needs of people with autism.



Source: National Audit Office survey of Local Authorities and NHS Partners

6 Relative difficulty of finding appropriate residential accommodation locally to meet the needs of people with autism

The majority of Local Authorities have difficulty finding appropriate residential accommodation locally to meet the needs of people with autism.



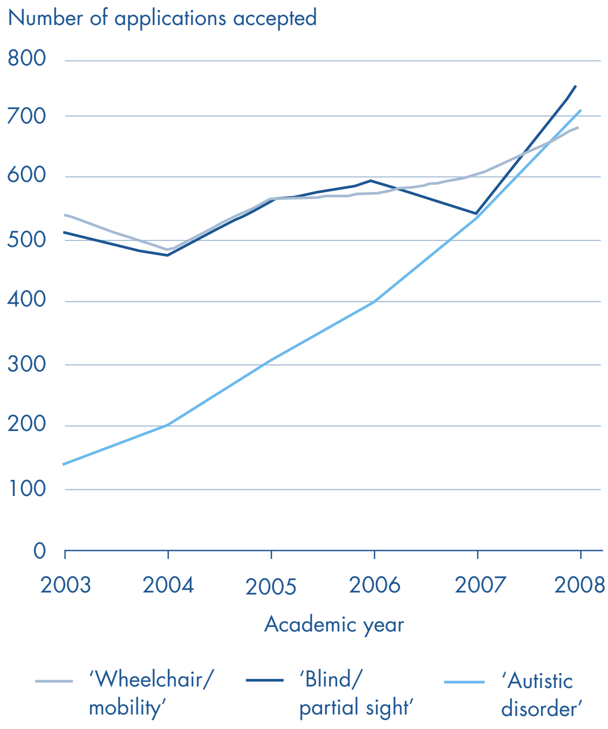
Source: National Audit Office survey of Local Authorities and NHS Partners

University students with autism and Disabled Students' Allowances

3.30 University is a major step for young people with autism owing to the change of routine, location and social environment. Without appropriate support they may not fulfil their potential and complete their degree. Over the six years 2003-2008, the number of accepted applicants to higher education with declared autism in the UK has risen by 408 per cent, from 139 to 706 **(Figure 7)**. This is a higher rate of growth than for any other disability (the next highest growth rate being 120 per cent for students who declared mental health difficulties, which increased from 495 to 1,089).

7 Numbers of accepted university applicants declaring they have autism, 2003-08

The number of accepted university applicants declaring they have autism is increasing rapidly



Source: UCAS data on applications to UK higher education courses, 2003-2008

3.31 People with autism at university are usually eligible to receive Disabled Students' Allowances to cover non-medical course-related costs,[57] and are generally receiving positive support in applying for and obtaining them. Data from the Higher Education Statistics Agency on the take-up of Disabled Students' Allowances shows that over half of the 1,455 students with autism pursuing a UK undergraduate or postgraduate course in 2007-08 receive Disabled Students' Allowances.

3.32 Disabled Students' Allowances can support retention and academic success for people with autism **(Case Example 3)**. Feedback we received from students, carers and HE disability advisors also suggested they generally meet students' needs, with up to around £23,000 per year available for students assessed as eligible.[58]

3.33 Disabled Students' Allowances are intended to help with the cost of a 'non-medical personal helper, items of specialist equipment, travel and other course-related costs'.[59] One issue frequently highlighted by people

CASE EXAMPLE 3

With appropriate support, students with autism can achieve positive educational outcomes

"Student B came for a prospective visit and we were struck by the severity of his symptoms – at the time he still responded to most kinds of stress by shutting himself in his room and curling in a foetal ball. He did not want to stay in halls for year one, preferred to stay at home, maybe try halls in year two. As the journey in by public transport was very complex (it involved two bus changes and walking through a crowded shopping precinct) the LEA agreed to fund taxi transport (20 minutes or less) as it was less stressful. We arranged both regular mentor support and a psychotherapist who specialised in autism – they supported him throughout, all funded by the DSA [...] Once B started University he did really well: the structured environment provided by his course suited him well and he loved it so much that by the end of the first term he decided he did want to live in halls after all. We arranged that from term two and he never looked back. He was a much more outgoing character and he thrived in the university environment. By year two he had a girlfriend and by year three he was sharing a house with a group of friends. He got a good degree, and last I heard was starting his doctorate." — Disability Advisor, University

Source: National Audit Office survey of higher education institutions

---

[57] http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/HigherEducation/DG_10034898.

[58] Based on maximum allowances for full-time courses, 2008-09: Specialist equipment (£5,030 for entire course), Non-medical helper (£20,000 p.a.) and General Disabled Students' Allowances (£1,680 p.a.). In addition to these allowances students can claim for 'reasonable spending' on extra travel costs for the academic year. Source: http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/HigherEducation/DG_070188.

[59] Student Finance England, *Bridging the Gap: A Guide to the Disabled Students' Allowances (DSAs) in higher education 2009/10*, p. 6 (http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/HigherEducation/DG_10034898).

with autism, carers and disability advisors in our web consultation and focus groups was that students with autism may need more support with the social side of university and future adult life than with purely academic, course-related matters. As in Case Example 3, an appropriate support package for a student with autism may include social mentoring. Disabled Students' Allowances assessors and higher education disability advisors need to be aware of this option when assessing need and designing support packages, but some are unaware that Disabled Students' Allowances can be used to fund social mentoring.

Access to benefits

3.34 People with autism may be eligible for a range of benefits including Disability Living Allowance, Employment and Support Allowance, Disabled Person's Tax Credit and Jobseeker's Allowance.

3.35 The approach taken by the Department for Work and Pensions to supporting people with a disability is increasingly 'pan-disability' rather than condition-specific, and they do not collect and report data on diagnosis when administering benefits. The Department tell us that they aim to practice a 'social' rather than 'medical' model of disability, focusing on people's needs rather than diagnostic 'labels'.

3.36 This approach is supported by many people with a disability, who may also wish to focus on having their needs met rather than being 'labelled' with a medical diagnosis. It does mean, however, that robust large-scale analysis of take-up, expenditure and outcomes for benefit applicants with autism is difficult, and that the Department cannot currently evidence either the amount it spends on benefits for this group or the extent to which it is meeting their needs. From October 2008, however, the Department has been recording whether new applicants for Disability Living Allowance have a diagnosis of autism or Asperger Syndrome, and this data will provide some basis for future quantitative analysis of applications and outcomes for people with autism.

3.37 Owing to the current lack of quantitative data, we employed qualitative methodologies to identify and explore the key issues around benefits for people with autism. These methods included an on-line web consultation involving 142 people with autism and 312 carers, in-depth interviews with autism specialists, service providers and Department for Work and Pensions staff, and focus groups with people with autism, carers and transition managers. The full list of participants in the interviews can be found at Appendix 1.

3.38 There was a widespread sense in our interviews and focus groups that the level of awareness of available benefits such as Disability Living Allowance and Carer's Allowance is patchy among people with autism and their carers. Many participants in our web consultation also reported difficulties identifying the benefits to which they might be entitled, and had often done so only by accident or through informal links such as carer groups.

3.39 Even where respondents were aware of their possible entitlement to benefits, they reported various accessibility barriers, primarily with regard to the claim process. The most commonly cited issue concerned benefit claim forms, particularly for Disability Living Allowance, which autism specialists, carers and people with autism felt were ill-suited to people with the condition. In particular, they felt the forms were excessively long and did not capture the restrictions encountered by people with autism (such as impaired social functioning), instead focusing chiefly on physical impairments. Other concerns related to social communication with advisors and the physical environment of Jobcentre Plus offices, which could be difficult for people whose autism made them sensitive to environmental factors such as noise and light levels.

> **'No one told me about benefits. I only found out about disability benefit [sic] through another mum with a child with ASD. I got no help filling in the very difficult and lengthy assessment form. It was difficult filling it in because it isn't applicable to Asperger's. It seems to be for physical disabilities. It was some time later before I applied for Carer's Allowance because I didn't know about it, and when I found out about it, I didn't realise that I qualified.'**
>
> *Parent of an adult with autism (Source: NAO consultation)*

3.40 Many of these difficulties and concerns were acknowledged amongst the Department for Work and Pensions staff interviewed. They suggested that existing facilities for completing claims on-line might be helpful for people with autism, and that Disability Employment Advisors with a knowledge of autism can play a useful signposting role for benefit claimants with autism. They also recognised, however, that claimants are not always aware of, or have not managed to access, a Disability Employment Advisor.

3.41 The other barrier cited in the consultations related to assessments of eligibility for benefits. Respondents reported that a lack of recognition and awareness of autism amongst benefits advisors had meant that some claimants had been directed to the wrong benefits, and others found that they were not eligible for higher rates because their impairments did not fit into the more easily recognised and accepted mental, physical and learning disabilities.

3.42 The Department for Work and Pensions recently issued updated autism guidance for Disability Living Allowance, which was developed with specialist input and in collaboration with the National Autistic Society. The revised guidance recommends the consideration of severe impairments in social functioning and useful intelligence in the decision, rather than focusing solely on I.Q. results. Where appropriate tests are unavailable, however, acceptance of the claim is at the discretion of individual decision makers, based partly on evidence provided to them by GPs and heath and social care workers who may themselves have low awareness of autism. Department for Work and Pensions and Jobcentre Plus staff we interviewed suggested that advisors sometimes had difficulty identifying specific needs because claimants had difficulties articulating them. Autism specialists emphasised the importance of medical input in informing assessors' awareness of claimants' needs, the varying quality of input to assessments provided by GPs and the difficulties experienced by claimants in obtaining a diagnosis to inform their assessment.

3.43 Recent reforms of Incapacity Benefit, which changed to the Employment and Support Allowance in October 2008, are likely to have an impact on people with autism. For example, the Work-Focused Health-Related Assessment[60] is performed by a healthcare practitioner, and is intended to assist Personal Advisers by outlining appropriate health and workplace interventions tailored specifically for the individual. Such reforms have the potential to improve the accuracy and consistency of needs assessments, provided that healthcare practitioners carrying them out have adequate awareness and knowledge of autism, and that the health and workplace interventions identified reflect the often specific and intensive support needs of people with autism (see below, paragraph 4.9).

The potential impact of personalised budgets on people with autism

3.44 The current reconfiguration of health and social care provision to place greater emphasis on personalisation (for example through individualised budgets) presents an opportunity to help people with autism obtain more appropriate services. For example, pilot appraisals of personalised budgets suggest that the ability to employ one care worker or pay informal carers was particularly beneficial for those who needed familiarity and routines, including people with autism.[61]

3.45 A recent review of services for people with complex needs (which include low-functioning autism) found that as yet few people with learning disabilities and complex needs are receiving personal budgets or direct payments. There was limited evidence of the provision of person-centred plans for such people, although there were moves towards more flexible commissioning arrangements in some areas.[62]

3.46 Respondents to both our Local Authority survey and our survey of third-sector autism organisations felt that personalised budgets would bring benefits for people with autism. Eighty-two per cent of third-sector organisations felt personalised budgets would allow more direct contact with service users, 78 per cent felt services would be more tailored to individual needs and 72 per cent said they would give users more choice.

3.47 Realising the benefits of personalised budgets for people with autism will require careful management, including appropriate advocacy, brokerage and mentoring services. The 26 per cent of respondents to our third-sector survey who disagreed that personalised budgets would allow for more effective service provision for people with autism cited the following risks.

- People with autism can struggle with handling money, and hence may find managing budgets stressful.
- Personalised budgets may lead to people with autism assuming employer responsibilities which they may require assistance to fulfil.

---

[60] See Glossary for details.

[61] IBSEN *Evaluation of the Individual Budgets Pilot Programme – Final Report* (October 2008), p. 54 (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505).

[62] Commission for Social Care Inspection, Healthcare Commission and Mental Health Act Commission, *Commissioning services and support for people with learning disabilities and complex needs: National report of joint review* (March 2009) (http://www.healthcarecommission.org.uk/_db/_documents/Report_for_commissioning_LD_joint_review.pdf).

- People with autism may only pay for services to meet their immediate needs rather than preventative services, advocacy or brokerage.
- Services with high fixed costs, such as residential care and telephone helplines, may struggle to survive the loss of fixed income from block contracts.

3.48 Local Authority survey respondents, while generally optimistic that personalised budgets would encourage flexibility, tailored services, choice and competition and greater efficiency, also highlighted a number of issues to be managed:

- the need to provide appropriate support for people with autism to manage their financial and contractual arrangements;
- the need for appropriate quality control of individual services; and
- the need to provide people with autism with sufficient information to make informed choices about available services.

Improving the effectiveness of services for adults with autism

Measuring the effectiveness of services for people with autism

4.1 People with autism may access a wide range of public services, as shown in Figure 3. As noted in Part 1, the data available on outcomes and contacts with services for adults with autism 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, as shown in Parts 2 and 3, it is likely that improving strategy and planning, and raising levels of knowledge and awareness of the nature of autism and the potential needs of autistic people, will improve outcomes for this group.

4.2 Specialised service provision for adults with autism, particularly those with Asperger Syndrome or high-functioning autism, is currently limited. There are, however, two types of specialised service which have been developed in a few areas of the country:

- employment support, including job preparation and coaching tailored to the needs of people with autism; and
- targeted multi-disciplinary health and social care support for people with high-functioning autism/Asperger Syndrome.

4.3 In this Part of the report, we examine the effectiveness of specialised health, social care and employment provision for adults with autism, and explore the possible costs and benefits of implementing such services more widely across the country. In particular, we analyse the potential impact of addressing the gap in services for adults with high-functioning autism/Asperger Syndrome, and providing this group with more targeted and effective health, social care and employment support.

4.4 To assess the potential impacts of such provision, we:

- reviewed existing evidence on costs and outcomes of the Department for Work and Pension's existing pan-disability employment support programmes;
- examined data and research on costs and outcomes of specialised employment programmes for people with autism;
- costed a number of existing specialist health and social care teams for people with high-functioning autism/Asperger Syndrome, including staff make-up and resources relative to local population size;
- used information from our Local Authority survey and data from specialised Asperger services to compare the probability of service users accessing various mental health and housing services with and without a specialised service in place; and
- constructed a model to compare the current baseline of service provision, costs and outcomes with a scenario where adults with high-functioning autism are provided with better targeted health, social care and employment support, achieving outcomes comparable with those of existing specialised services.

Employment support for people with autism

4.5 Regular employment can bring psychological and social benefits to people with autism, including increased self-esteem and better social integration **(Case Example 4)**, as well as potentially generating financial and economic benefits through increased productivity and reduced benefit payments. A recent survey found that only 15 per cent of all adults with autism are in full-time employment.[63]

---

[63] 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%20acrt%20pos.pdf).

4.6 The Department for Work and Pensions' approach to supported employment is pan-disability rather than disability-specific. The type of support provided by disability employment providers, such as work preparation and in-work support, is important for people with autism. An individualised approach also helps people who are at different points on the autistic spectrum obtain a wide range of support.

4.7 Autism specialists we interviewed nonetheless felt that the Department for Work and Pensions' focus on job outcomes in contracts created a risk that providers would focus on groups who are easier to place and therefore more cost-effective to help. There were also concerns that people with autism might be overlooked because they would be more difficult to move into work, or that employment support services focused on short-term support that move a person into work quickly, but do less to address the longer-term support needs for sustainable employment.

4.8 Other concerns expressed by people with autism, their carers and autism specialists regarding the appropriateness of pan-disability employment provision for people with autism included: reliance on group work, which some people find difficult because of social anxiety, and short-term focus on producing job outcomes rather than building confidence and trust, which is particularly important for people with autism (Case Example 4). Carers also expressed concern over their lack of involvement where services had low awareness of autism. They felt there was a risk that staff would not obtain correct information without this involvement because people with autism can have communication difficulties, be easily agreeable and cannot always understand nuanced questions.

> **'A lot [of employment support services] have been contracted out to private companies who just have targets, and often what you'll find is people that have high support needs are dropped.'**
>
> *Autism Specialist (Source: NAO consultation)*

> **'Whoever is undertaking the assessment will try and discuss with the customers what barriers they have and how it is going to affect their participation in the programme, but also the ultimate aim is that we get them into the job market as soon as possible.'**
>
> *Disability employment contract manager (Source: NAO consultation)*

CASE EXAMPLE 4

People with autism benefit from specialised autism-specific support to develop social and employment skills

Paul is in his early twenties, and has a diagnosis of Asperger Syndrome. As part of the Prospects 'Brighter Horizons' course, which is designed to develop work-related skills and support individuals to find and undertake an extended voluntary placement, Paul attended weekly group workshops on subjects such as coping at work, facing the future, workplace relationships and healthy living. He enjoyed these sessions very much, as he got the chance to mix with other individuals with Asperger Syndrome and share ideas and experiences with them. Paul also attended weekly one-to-one sessions with a Prospects advisor, focusing on areas such as conversation skills and how to interpret body language, as well as appropriate and inappropriate topics of conversation at work.

Paul has a keen interest in retail work, and has always wanted to work in a supermarket. Prospects arranged an eight-week supported placement as a grocery assistant at a local supermarket, replenishing the stock in various departments, collecting stock from the warehouse and helping customers with their shopping. He worked three days per week for five hours per day.

Paul's Prospects advisor visited him every week while he was on placement, observing him working and discussing with him how everything was going, as well as meeting with Paul's supervisor to talk about any issues arising. His colleagues were very supportive and friendly, and Paul was receiving extremely positive feedback on the work he was doing. Paul's Prospects advisor noticed that his confidence was increasing, and Paul made it clear that he was thoroughly enjoying his time at work. He liked the work because it felt good keeping busy, and gave him a sense of responsibility. He liked having a routine structure to his life and hoped that one day he could get a 'real' job like this one.

On the last day of Paul's placement, his Prospects advisor met with his supervisor, who said that Paul had actually been working harder than most of the full-time employees, that he would love Paul to be part of his team, and asked Paul if he would like to join the team as a paid employee when a role became available. Paul was delighted and is currently waiting for a vacancy to become available on the shop floor. In the meantime, he has continued to come to Prospects each week to develop further the attitudes and skills that will enable him to succeed in the workplace.

Source: National Audit Office/National Autistic Society 'Prospects' Service

Specialised autism employment support

4.9 Specialised supported employment schemes for people with autism involve working with individuals to prepare them for employment, finding them appropriate work experience and jobs, and employing a job coach to work alongside them in the workplace. The evidence base regarding the effectiveness of such schemes is currently small, but suggests that they can result in significantly higher rates of employment, more appropriate employment, greater job satisfaction and higher employer satisfaction when compared to generic disability employment services, and that such gains are maintained over time.[64] In addition to improved quality of life, better mental and physical health and reduced carer burden, the evidence also suggests that the initial costs of such support, though high, can usually be recovered in up to seven years.[65]

4.10 One of the few specialised employment services for individuals with autism in the UK is 'Prospects', which was established by the National Autistic Society in 1994. It receives the majority of its funding from the Department for Work and Pensions and one-off grants from charitable organisations and business enterprises. The service offers work-preparation programmes, job-finding support, interview support and in-work support tailored to the needs of job seekers with autism and Asperger Syndrome (Case Example 4).

4.11 Prospects has been subject to a long-term academic evaluation covering numbers and types of jobs found, characteristics of clients, economic costs and benefits, and satisfaction levels.[66] This evaluation indicated that Prospects maintained good levels of success, with the overall proportion of clients who were supported into work increasing from 63 per cent to 67 per cent. Although the client group was more representative of higher-functioning autism or Asperger Syndrome, the scheme showed evidence of meeting the needs of those with more complex demands. The study revealed that over 85 per cent of the jobs gained were sustained (over 13 weeks), and clients reported good satisfaction levels, increased confidence and improvements in independence, with salaries increasing significantly and reliance on benefits decreasing.

4.12 The evaluation suggested that the cost per job found by Prospects decreased from £6,542 in 2000-01 to £4,281 in 2002-03. Between 1 April 2000 and 31 March 2003, the Department for Work and Pensions provided Prospects with a total of £673,781. The overall benefits to the Exchequer over that time, in terms of reduced benefit payments and income from tax and National Insurance, was £494,686, i.e. a net cost of £179,095 for providing 114 jobs. Thus while the financial costs of running Prospects were high, the employment outcomes were good, and sizeable savings on benefit expenditure were made, notwithstanding the associated improvements in individuals' quality of life and general health.

4.13 Further evaluation is needed to determine how the various elements of the Prospects model (such as work preparation, job coaching or employer awareness training) contribute to successful outcomes, and hence how these outcomes might be replicated more widely within the Department for Work and Pension's supported employment programmes. For example, specialist job coaches with knowledge of autism could also be provided through pan-disability provider organisations, and funded through Jobcentre Plus programmes such as Access to Work, or the reformed specialised disability programme which is planned to replace Workstep, Work Preparation and the Job Introduction Scheme from October 2010. Contracts and funding arrangements for the new programme would however need to reflect the specialised knowledge, relatively long preparation times and ongoing support required to produce successful employment outcomes for adults with autism. Hence, in modelling the potential costs and benefits of wider provision of employment services able to produce outcomes comparable to those of Prospects, we have also assumed higher costs comparable with those of Prospects.

Specialised services for people with high-functioning autism and Asperger Syndrome

4.14 In a few areas of the country, local health and social care organisations have set up a specialised service specifically for adults with high-functioning autism. This service may take the form of a multi-disciplinary team dedicated solely to clients with high-functioning autism/ Asperger Syndrome **(Case Example 5)**, or an autism specialist (for example a consultant neuro-developmental psychiatrist) working in conjunction with existing services such as Community Mental Health Teams.

---

[64] See Robertson J and Emerson E, *A Systematic Review of the Comparative Benefits and Costs of Models of Providing Residential and Vocational Supports to Adults with Autistic Spectrum Disorder* (National Autistic Society, 2006), p. 2 (http://www.autism.org.uk/content/1/c6/01/06/11/review.pdf).

[65] Howlin P, *Autism and Asperger Syndrome: Preparing for Adulthood* (Routledge, 2004), p. 240.

[66] Howlin P, Alcock J, Burkin C, 'An 8 year follow-up of a specialist support employment service for high-ability adults with autism or Asperger syndrome' in *Autism* 9(5) (2005).

CASE EXAMPLE 5

Liverpool Asperger Syndrome Team

The Liverpool Asperger Syndrome service was set up in 2003 so that people with Asperger Syndrome who were not eligible for either Learning Disability or Mental Health services would have specialised support and a direct route into multi-disciplinary services. The team is jointly commissioned by Central Liverpool Primary Care Trust and Liverpool Social Services, and consists of a Team Manager who is also a speech and language therapist, two community nurses, a psychologist (0.8 whole-time equivalent), a social worker, three support workers and an administrator.

Since April 2003 the team have had 549 referrals, and are currently actively supporting 137 people. Clients do not require a formal diagnosis of Asperger Syndrome to be referred to the service, as the team also carry out diagnostic assessments. Acting as a central point of access from assessment and diagnosis, the team provides its clients with ongoing care management and co-ordinates a range of other services, including employment support, education, service-user and carer groups, mental health, criminal justice liaison and alcohol/substance misuse services.

Source: National Audit Office/Liverpool Asperger Syndrome Team

4.15 The exact staff mix of such services varies between localities (**Figure 8**), although all include multi-disciplinary autism specialist input and offer both diagnostic assessment and support services. Adjusting for differences in local population size, two of the three (Liverpool and Kingston) cost approximately the same (around £1,400 per 1,000 of population served). Although equivalent costs for the third team (Northamptonshire) are much lower, the team report that they currently have difficulty meeting demand, particularly for diagnostic assessments. For the purposes of our modelling, therefore, we have assumed costs equivalent to Liverpool and Kingston (Appendix 2).

Effectiveness of specialised health and social care services for people with high-functioning autism

4.16 Available data on outcomes and service use for clients of specialist health and social care teams for adults with high-functioning autism are limited, partly because of the small number of such services currently in existence, and partly because most have been set up

8 Staff mix and costs of existing specialised Asperger services

		Liverpool	Kingston	Northamptonshire[1]
2007 working-age (16-59/64) adult population (000)		284.6	106.6	425.9
Team Staffing (Whole-Time Equivalent)	Consultant Psychiatrist	0.00	0.00	0.00
	Clinical psychologist	0.80	0.50	2.00
	Occupational Therapist	0.00	0.20	1.00
	Community Psychiatric Nurse/Social Worker	3.00	1.00	1.00
	Support Worker	3.00	1.20	0.00
	Admin/Secretary	1.00	0.20	0.30
	Team Manager	0.50	0.40	0.00
	Speech and Language Therapist	0.50	0.20	0.00
Estimated Cost (£)		369,421	163,713	240,073
Estimated cost per 1,000 of working-age (16-59/64) adult population (£)		1,298	1,536	564

Source: National Audit Office analysis of ONS population estimates, individual service specifications and discussion with service providers. Costs are taken from Curtis L, Unit Costs of Health and Social Care (Canterbury: Personal Social Services Research Unit, 2008), and where relevant include costs of qualification and autism-specific further training annuitised over the individual's working life. For more details of unit cost assumptions, see the accompanying modelling paper on the NAO website (www.nao.org.uk).

NOTE

1 The Northamptonshire service also cover other developmental disorders such as Attention Deficit Hyperactivity Disorder, but estimate that approximately half of their resources are dedicated to high-functioning autism/Asperger Syndrome. The figures used here are therefore half of the whole-time equivalent team specification.

relatively recently. Comparing their effectiveness with mainstream provision is difficult because their client group have generally failed to access mainstream services, or have done so through inappropriate channels such as acute mental health teams, where their autism may not be recognised and recorded to allow interventions and outcomes to be compared.

4.17 Nevertheless, evidence from our survey of Local Authorities, from analysis of data for specialised services that do exist, and from evaluations of specific elements of such a service, for example employment support, suggests that providing multi-disciplinary support can result in greater independence and better access to services for adults with high-functioning autism. For example, we analysed anonymised data from two services to compare the proportion of time spent by their clients in mental health crisis resolution treatment before and after they were diagnosed and supported by the service. In one service, of the 14 clients who had required crisis resolution treatment prior to obtaining a diagnosis and accessing support, none had done so in the equivalent period following diagnosis. In the other, the likelihood of accessing crisis services increased slightly after diagnosis, suggesting that the team may be facilitating access for clients with mental health problems to services they might otherwise not have received.

4.18 Analysis of anonymised hospital admissions data from the two services showed a similar pattern. Acute mental health admissions rates for some clients were significantly lower after they were identified for ongoing support by the multi-disciplinary team. For other clients, the probability of admission could go up, again suggesting that the team may be facilitating access for clients to services they require.

4.19 There is also evidence that clients supported by a specialised service are able to live in more independent and cost-effective housing than those who are not. Our survey of Local Authorities suggested that, where data were available, the average proportion of adults with high-functioning autism known to services and living in inpatient or residential housing settings was lower in areas with a specialised service than without. Supporting an adult with autism to live independently in their own home costs social services approximately £60,000 less per year than housing them in a residential placement.[67] Local Authorities without specialised services in place reported, where figures were available, that about seven per cent of adults with high-functioning autism were in residential settings, compared with less than one per cent in one area with a specialised service.

The potential costs and benefits of providing more effective and appropriate services for adults with high-functioning autism

4.20 **Box 3** summarises some of the ways we identified in which effective specialised services for adults with high-functioning autism can improve outcomes for them and their carers.

4.21 To explore the possible benefits of providing comprehensive multi-disciplinary services for adults with high-functioning autism and Asperger Syndrome across England, we used existing research and bespoke data collected from local services to construct an economic model. The model, which is outlined in more detail in Appendix 2, compares the costs of current service provision against the cost of providing more autism-specific support in the areas of health and social care, housing and employment. Whilst more data collection and analysis would be needed to produce a year-on-year cost-benefit appraisal to inform detailed service development, the model uses the best available existing evidence to explore the scope for value-for-money improvements in service provision for adults with high-functioning autism.

BOX 3

Potential improved outcomes from specialised support services

An effective service support service for high-functioning autism offers assessment and diagnosis, multi-disciplinary clinical input, case management by a trained keyworker and access to related services such as employment support. Such services improve outcomes for people with autism and their carers by:

- facilitating access to diagnosis;
- reducing the incidence of mental health problems;
- increasing the likelihood of being in employment;
- increasing the likelihood of more independent living; and
- reducing family expenses and lost employment for parent carers.

Source: National Audit Office analysis of outcome data and published evaluations

---

[67] Source: Knapp et al., *The Economic Costs of Autism in the UK*, p. 18.

4.22 Costs for the various elements (such as specialist staff and employment support programmes) were based on figures from existing services, while the probabilities of accessing various types of provision, and hence the estimated improvements in the outcome measures listed in Box 3, were based on case data from existing services and previous research.

4.23 The model suggests that, in addition to the quality-of-life improvements of providing appropriate support to people with autism, such provision could also result in benefits to the public purse through reduced costs for local authority services, and reduced benefit payments, as well as reducing expenses for carers and individuals. The key determinants of whether such benefits are realised would be:

- the proportion of the local population with high-functioning autism/Asperger Syndrome which the service could identify;
- the proportion of its clients in supported housing or residential care who could more cost-effectively be cared for in private households; and
- the proportion of its clients finding employment.

4.24 The few such specialised services currently in existence were mostly established in the last two or three years, and hence are unlikely yet to have achieved their maximum potential identification rates. Data from one of the oldest such services, the Liverpool Asperger team (established 2003), indicate that around 14 per cent of the estimated local population with high-functioning autism / Asperger Syndrome have been identified and are known to local services. 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 over time become cost-neutral for overall public expenditure, as well as resulting in additional earnings and reduced expenses for individuals.

4.25 Our model suggests that 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, a six per cent identification rate could lead to potential savings of £38 million per year, and an eight per cent to savings of £67 million. Under these same scenarios, there could also be additional financial benefits to individuals of around £10 million and £13 million per year respectively, in the form of increased gross earnings (for both people with autism and their carers) and reductions in family expenses **(Figure 9)**. 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.

4.26 We have estimated costs for the reconfigured services, for example an additional £40 million per year to provide multi-disciplinary specialist teams across the whole of England.[68] However, achieving the potential benefits would also require good planning and management and the commitment of all local delivery partners, as impacts may be felt elsewhere in the system rather than by the lead organisation funding the service. For example, the benefits of preventative services funded by NHS bodies may be felt by Local Authorities (for instance through reduced housing costs) rather than NHS bodies themselves. 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.

9 Estimated annual financial costs/(benefits) of implementing effective specialised services for people with high-functioning autism, assuming a range of possible identification rates

Identification rate	2%	4%	6%	8%
Estimated annual cost/(benefit) to public purse (£m)	22.3	(6.4)	(38.2)	(66.8)
Estimated annual cost/(benefit) to private individuals (including gross earnings) (£m)	(6.4)	(6.4)	(9.5)	(12.7)

Source: National Audit Office analysis

---

[68] Assuming an average cost of £1,400 per 1,000 of working-age adult population (paragraph 4.15), and an approximate baseline of existing specialist provision of 10 per cent (paragraph 3.12), this equates to an approximate cost of : 1,400 x 31,800 x 90 % = £40 million. These costs include annuitised estimates for training costs.

APPENDIX ONE

Methodology

1 We designed this study to examine the range of services that might be needed by people with autism, including health and social care, education, benefits and employment. We explored the problems and challenges of delivering services to people with autism, assessing the baseline of service provision (including good practice) and recommending how this baseline could be improved to address the problems and challenges identified. The main strands of our methodology are set out below.

Survey of Local Authorities and NHS partner organisations

2 We surveyed all 150 Local Authorities[69] with Social Services Responsibilities in England, requesting data from both themselves and their NHS partners on identified need, strategy and planning, expenditure and service provision for people with autism. The survey was completed between September 2008 and February 2009, and 111 of 150 Local Authorities (74 per cent) submitted a return.

Survey of General Practitioners

3 We commissioned Doctors.net.uk (which provides Internet services to some 142,400 doctors across the UK) to conduct an on-line survey of 1,000 GPs in England, covering:

- numbers of patients presenting with symptoms of autism;
- referral pathways for patients whose symptoms indicate that they have autism;
- ongoing support, monitoring and condition management provided for patients with autism;
- confidence levels among GPs that patients in their area with autism are receiving appropriate and adequate care; and
- GPs' views as to the adequacy of current guidance and training to help them identify and manage patients with autism.

The survey was conducted between 23 September and 10 October 2008. A total of 1,000 responses were obtained, covering all Strategic Health Authority areas in England. In addition to the analysis and report provided by Doctors.net.uk (available on the NAO website), the NAO conducted further in-house analysis and coding of the qualitative responses received to open questions.

Survey of Disability Support Officers in further and higher education institutions

4 We conducted a short web-based survey of Disability Support Officers in further and higher education institutions in England, requesting information about their experiences of supporting students with autism, training for staff, students' retention and success rates, and links with the Connexions service and other agencies. The survey ran from 31 October to 30 November 2008. We received responses from 67 of 127 higher education institutions (a 53 per cent response rate), and from 103 of 365 further education institutions (a 28 per cent response rate).

Survey of third-sector providers of services for adults with autism

5 We commissioned MORI to conduct telephone interviews with third-sector organisations (TSOs) across the UK that provide services for adults with autism. Questions were asked about various aspects of the commissioning process and about the benefits and challenges of personalised budgets. The survey was conducted between 13 October and 21 November 2008.

---

[69] Changes to local government mean that from 1 April 2009 there are 152 Local Authorities in England.

There were 291 responses, of which 163 TSOs have provided or are currently providing services to Local Authorities, Primary Care Trusts or Mental Health Trusts. We then conducted follow-up telephone interviews with 18 respondents to gain a greater understanding of the responses given and the reasons behind them. These were conducted between 27 November and 15 December 2008.

Focus groups and web consultation

6 We worked with the National Autistic Society (NAS) to convene and facilitate twelve focus groups exploring the views and experiences of adults with autism and their carers. These groups covered topics such as health and social care, transition, further and higher education, benefits and employment, and took place between 22 September and 17 October 2008. We also ran a public web consultation via the NAS website, inviting contributions from people with autism and their carers under the same thematic headings. This was open between 24 September and 31 October 2008, and 455 responses were received, 142 from people with autism and 312 from carers.

Review of the Department for Work and Pensions' support for people with autism

7 We commissioned the Centre for Economic and Social Inclusion (Inclusion) to examine the role and effectiveness of the Department for Work and Pensions in providing employment support and benefits for people with autism. The research included an examination of:

- transition support services for individuals with autism;
- mainstream, pan-disability and specialist employment support services,
- the benefits system, particularly the clarity and consistency of eligibility criteria and understanding of the system amongst claimants with autism; and
- support provided for carers of people with autism.

The methodology for this work included a literature review, in-depth interviews with Department for Work and Pensions and Jobcentre Plus staff and autism specialists, and focus groups with individuals with autism, carers and transition managers. Thematic content analysis of interview and focus group transcripts was undertaken using the software programme Atlas.ti. The full report of the work is available on the NAO website, and the individuals and organisations that took part are shown in **Box 4 overleaf**.

Economic modelling

8 We constructed a decision-tree model to assess the economic impact of providing comprehensive multi-disciplinary services for adults with high-functioning autism / Asperger Syndrome across England. The model was developed to compare the costs of current service provision against the cost of providing more specialist support in the domains of health and social care, housing and employment. Probability and cost values for the model were obtained from our survey of Local Authorities, detailed analysis of cost and caseload data from existing specialist services, published figures and expert opinion. Sensitivity analyses were carried out to test the robustness of the model under a wide range of probabilities and costs. Appendix 2 summarises the methodology and findings, and a paper describing the model in more detail can be found on the NAO website *(www.nao.org.uk)*.

Use of existing data and research

9 In addition to drawing on a range of existing academic research and other literature, we performed our own analysis using:

- costs, caseload and mental health patient histories within a number of specialist Asperger Syndrome services; and
- data from the University and Colleges Admissions Service and the Higher Education Statistics Agency on applications and university entrants.

Interviews with key stakeholders

10 We conducted interviews with policy personnel from the Department of Health, the Department for Work and Pensions, the Department for Children, Schools and Families and the Department for Innovation, Universities and Skills to establish the position on policy and strategy for people with autism. We met with numerous stakeholders in the field of autism, including academics, clinicians, service providers from the statutory, private and voluntary sectors, national and local charities and support groups, and people with autism and their carers.

BOX 4

Organisations and individuals participating in our review of benefits and employment support for adults with autism

Mainstream Services

Organisation	Job Title
Disability and Carers Service	Project Manager for the Customer Case Management Project
Department for Work and Pensions	Contract Manager (x 2)
Department for Work and Pensions	Customer and External Relations Director
Department for Work and Pensions	Delivery Manager, NDDP and Private-led Pathways
Department for Work and Pensions	Head of Pensions Policy team
Department for Work and Pensions	Senior Delivery Manager
Health Work and Wellbeing Directorate	Deputy Director
Jobcentre Plus	Disability Employment Advisor (x 2)
Parental Employment Division	Employment and Policy for Carers
Pension, Disability and Carers Service	DCS Customer Consultation Manager
Work Directions	Employment Advisor (x 2)

Specialist Services

Organisation	Job Title
Aspire	Regional Development co-ordinator
Autism Plus	Director of Public Health
EmployAbility	Employment Adviser
Bury EST (employment support training)	Employment Officer
National Autistic Society	Policy and Campaigns Officer, (with focus on employment and benefits)
Princess Royal Trust for Carers	Assistant Director
Prospects	Employment Consultant
ROSE Realistic Opportunities for Supported Employment	Project Manager
SAFE Supporting Asperger Families in Essex	Chair
Kingwood Trust	Chief Executive
Treehouse	Director of Educational Policy and Development

Transition Managers

Organisation	Job Title
Birmingham City Council	Head of Transition
Colleges	Outreach Transitions Worker
Dimensions	Acting Area Manager/Regional Transitions Lead
Local government	Contact and Assessment Worker
Hertfordshire City Council Money Advice Unit	Benefits Adviser for Children with Disabilities
National Autistic Society	Senior employment manager
Partners in Autism	Project Manager
Transition Information Network	Programme Coordinator (Policy and Planning)

11 In addition, we are grateful to the following individuals for their advice and assistance in producing this report:

Christine Asbury, formerly Chief Executive, Kingwood

Dr Maggie Atkinson, President, Association of Directors of Children's Services (ADCS)

Wendy Atkinson, Autism Development Manager, Oldham Metropolitan Borough Council

Christine Austin, Team Manager, Liverpool Asperger Team

Professor Anthony Bailey, Department of Psychiatry, Oxford University

Nicola Bailey, Director of Adult and Community Services, Hartlepool Borough Council and co-chair, ADASS Learning Disabilities Network

Dr Gillian Baird, Consultant Developmental Paediatrician, Guy's and St Thomas' NHS Trust

Penny Banks, Head of Information and Reporting, Commission for Social Care Inspection

Andrew Barlow, Social Worker, Liverpool Asperger Team

Professor Simon Baron-Cohen, Director, Autism Research Centre, Cambridge University

Amanda Batten, Head of Policy and Campaigns, National Autistic Society

John Bercow MP

Andrea Biggs, Employment Development Manager, Kingston Workstart

Kenny Braidwood, Head of Service, Learning Difficulties, South Gloucestershire Council

Christine Breakey, Support Coordinator, The Sheffield College

Richard Bremer, Goldman Sachs

Maria Bremmers, Project Manager, Autism London Partners in Autism Network

Dr Tony Brown, Consultant Clinical Psychologist, Autism Diagnostic Research Centre, Southampton

Professor Terry Brugha, Consultant Psychiatrist, Leicestershire Partnership NHS Trust

Sarah Capstick, Information and Communications Officer, Crossroads

Mel Carr, Senior Regional Officer (South East), National Autistic Society

Sarah Caton, Assistant Director, Association of Directors of Children's Services (ADCS)

Dr Frank Chapman, Clinical Psychologist, Liverpool Asperger Team

Roderick Cobley, Chair, London Autistic Rights Movement

Bryan Coleman, Disability Support Officer, University of Manchester

Mary Colley, Developmental Adult Neuro-Diversity Association

Sasha Daly, Policy and Parliamentary Manager, Treehouse

Norman Darwen, Manchester Officer, National Autistic Society Prospects

Huw Davies, British Association for Supported Employment

Karen Davies, Planning Officer, Leicestershire Adult Mental Health Services

Paul Davies, Service Director, Adult Social Care, Oldham Metropolitan Borough Council

Paul Dempsey, Forensic Mental Health Service, Leicestershire Partnership NHS Trust

Sue Disley, Assistant Director, Adult Social Care Service, Leicestershire County Council

John Dixon, President, Association of the Directors of Adult Social services (ADASS)

Christina Earl, Team Manager, EmployAbility, Surrey County Council

Carol Evans, National Director, National Autistic Society Scotland

Jenny Fisher, Carer Representative, Leicester Asperger Planning Team

Dr Andrew Flynn, Consultant Psychiatrist, Oxleas NHS Trust

Alex Fox, Director of Policy and Communications, Princess Royal Trust for Carers

Steve Francis, Business Manager, Bexley Mental Health Services

Sarah Garry, Service Co-ordinator, Kingston Asperger Service

Hilary Gilfoy, UK Chief Executive, Autism Speaks

Katie Glover, Strategic Joint Commissioning Manager, Learning Difficulties, West Sussex County Council

Sue Green, independent mentor for people with autism

Kate Groucutt, Senior Policy and Public Affairs Officer, Carers UK

Kate Gurner, Head of Director's Office, Adult Services, Hampshire County Council

Dr Elisabeth Hill, Department of Psychology, Goldsmith's College

Netta Hollings, Programme Manager, Community and Mental Health, The Information Centre for Health and Social Care

Professor Patricia Howlin, Professor of Clinical Psychology,University of London

Kathryn Hudson

Glynn Hughes, Developmental Adult Neuro-Diversity Association

Carolann Jackson, Chair, Supporting Asperger Families in Essex (SAFE)

Iona Joy, Head of Health and Disability, New Philanthropy Capital

Jo-Anne Keys, Family Support Officer, Autism Anglia

Professor Martin Knapp, Professor of Health Economics, University of London

Sarah Lambert, Policy Officer, National Autistic Society

Jenny Leitch, Head of Partnerships and External Relations, Crossroads Association

Jane Mackenzie, England Policy Officer, Royal College of Speech and Language Therapists

Andrea MacLeod, University of Birmingham

Geoffrey Maddrell, Chairman, Research Autism

Dr Nicola Martin, Principal Lecturer in Inclusive Practice, Sheffield Hallam University

Melissa McAuliffe, East London NHS Trust

Andrew McCulloch, Chief Executive, The Mental Health Foundation

Barbara McIntosh, Co-Director, Foundation for People with Learning Disabilities

Dr Richard Mills, Director of Research, Research Autism

Thomas Moore, Autism Project Manager, Surrey County Council

Hugh Morgan OBE, Welsh Assembly Government Autism Lead

James Morgan, Morgan Harris Burrows

Claire Moser, Policy Officer, Royal College of Speech and Language Therapists

Dr Raja Mukherjee, Neuro-Developmental Consultant Psychiatrist, Surrey and Borders Partnership NHS Trust

Peter Murphy, Director of Community Care and Housing South Gloucestershire and co-chair, ADASS Learning Disabilities Network

Dr Dinah Murray, Campaigns Coordinator, Autreach

Janet Muscutt, Senior Educational Psychologist, Salford City Council

Dr Jamie Nicholls, General Practitioner

Dr Deirdre O'Brady, Consultant Psychiatrist, Newham Primary Care NHS Trust

Anna Ostmeier, Policy and Participation Officer, National Autistic Society

Michael Parsonage, Policy Advisor, Sainsbury Centre for Mental Health

Robert Pasterfield, Autism Project Worker, Wokingham Mencap

Pratima Patel, Adult Planning and Service Development Officer, Leicester City Council

David Perkins, Manager, National Autistic Society Prospects

Carol Povey, Head of Adult Services, National Autistic Society

Linda Redford, Director of National Development, Treehouse

Sarah Redman, Social Policy Researcher, National Autistic Society

Dr Kobus van Rensburg, Clinical Psychologist, Northamptonshire Healthcare NHS Trust

Colin Revell, NeuroDiversity and Autism Action Group

Fiona Ritchie, Learning Disability Advisor, Healthcare Commission

Nick Rogers, Director of Resources, National Autistic Society

Renee Romeo, Institute of Psychiatry, University of London

Mia Rosenblatt, Policy and Research Officer (Adults), National Autistic Society

Mari Saeki, Family Services Development Project, National Autistic Society

Susan Scott-Parker OBE, Chief Executive, Employers' Forum on Disability

Professor Geoff Shepherd, Sainsbury Centre for Mental Health

Elaine Shilcock, Head of Disability Support, University of Manchester

Dame Stephanie Shirley

Dr Paul Skirrow, Chartered Clinical Psychologist, Liverpool Asperger Team and Learning Disabilities Directorate, Mersey Care NHS Trust

Annabel Smith, Goldman Sachs

Marie Southern, Community Nurse, Liverpool Asperger Team

Andrew Stamp, Morgan Harris Burrows

Madeline Starr, Carers and Employment Manager, Carers UK

Dr Geraldine Strathdee OBE, Consultant Psychiatrist and Clinical Director, Oxleas NHS Foundation Trust

Russell Stronach, Co-Chair, Autistic Rights Movement UK

Paul Swift, Research Fellow, Foundation for People with Learning Disabilities

Dr Alison Tierney, Department of Social Medicine, University of Bristol

Janet Tuohy, Head of Support Services, Salford City Council

Dr Vicky Turk, Joint Clinical Director & Head of Clinical Psychology Speciality (Learning Disabilities), Oxleas NHS trust

Sarinda Vetley, Manager, Leicestershire Adult Mental Health Services

Ester Vickers, Regional Coordinator (Central), National Autistic Society

Rhiannon Walters, Chair, Autism London

Caroline Waters, Director, People and Policy, BT Group

Debbie Waters, Family Services Development Project, National Autistic Society

Sue Williams, Research Manager, Kent County Council

Heather Wood, Head of Adult Care, Northumberland Care Trust

Adrian Wyatt, Co-Chair, Autistic Rights Movement UK

Dr Joanne Yarker, Department of Psychology, Goldsmiths College

Jonathan Young, Goldman Sachs

APPENDIX TWO

Economic modelling

1 In order to analyse the potential financial impacts of providing specialist multi-disciplinary services for adults with high-functioning autism/Asperger Syndrome across England, we developed an economic model. The model compares the costs of current service utilisation against the cost of service utilisation under the scenario where more specialist support is provided in the domains of health and social care, housing and employment. As shown in Part 4 of the main report, the available evidence suggests that providing support of this kind can increase the probability that adults with high-functioning autism achieve better outcomes in areas such as employment and housing settings. This in turn can lead to reduced overall costs of service utilisation. The net financial impact of providing a comprehensive multi-disciplinary service for adults with high-functioning autism/Asperger Syndrome is estimated from the model as the difference between the total cost of service utilisation with and without a specialist service in place.

2 Probability and cost values for the model were obtained from our survey of Local Authorities and their NHS partners, detailed analysis of cost and caseload data from existing specialist services, published figures and expert opinion. The following is a summary of the model, the assumptions made in its construction, and the main findings generated. A more detailed explanation, including full details of all model parameters, and details of the extensive sensitivity analyses we ran to study the effects of uncertainty in these parameters, is available on the NAO website, at *www.nao.org.uk*.

The model

3 The model is a decision analytic model constructed using the software package Treeage 2008 Professional. **Figure 10** shows the model structure.

4 The model sets out a 'snapshot' view of the annual pattern of service utilisation by adults with high-functioning autism, following the 'care pathway' of such adults, from detection, through intervention and support to outcomes in terms of employment, accommodation and healthcare. It compares costs to the public purse under two scenarios: one where a specialist service is provided for adults with high-functioning autism through a multi-disciplinary team of health and social care professionals (including specialist employment support), and one where it is not. **Figure 11** and **Figure 12 overleaf** illustrate the care pathways and different levels of service utilisation the model attempts to reconstruct.

5 The model combines prevalence estimates, identification rates and probability of service utilisation to estimate levels of service utilisation at a cohort level. This information is then combined with unit costs estimated for different services to obtain the total cost of service utilisation.

Probabilities

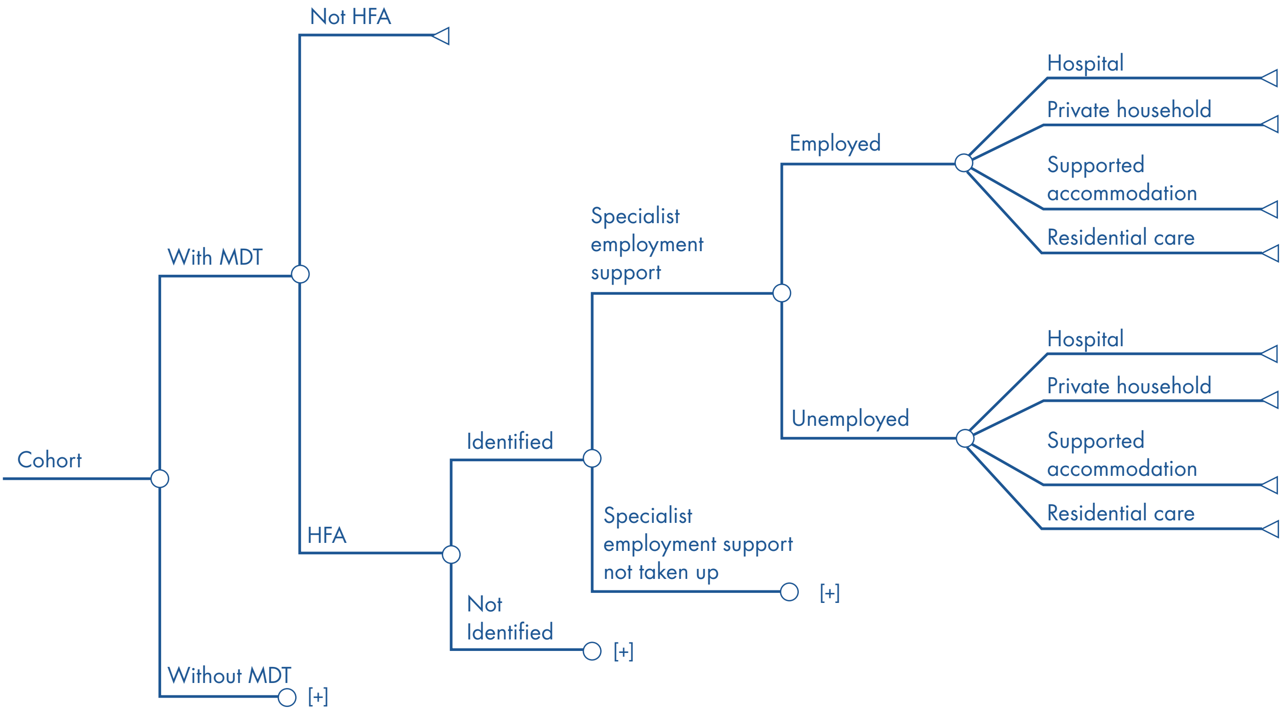
6 Probabilities are estimated using results obtained from the NAO survey of Local Authorities and their NHS partners, and from more detailed data supplied by local service providers where possible. Otherwise they were obtained from published literature.

Costs

7 The following categories of costs are included in the model:

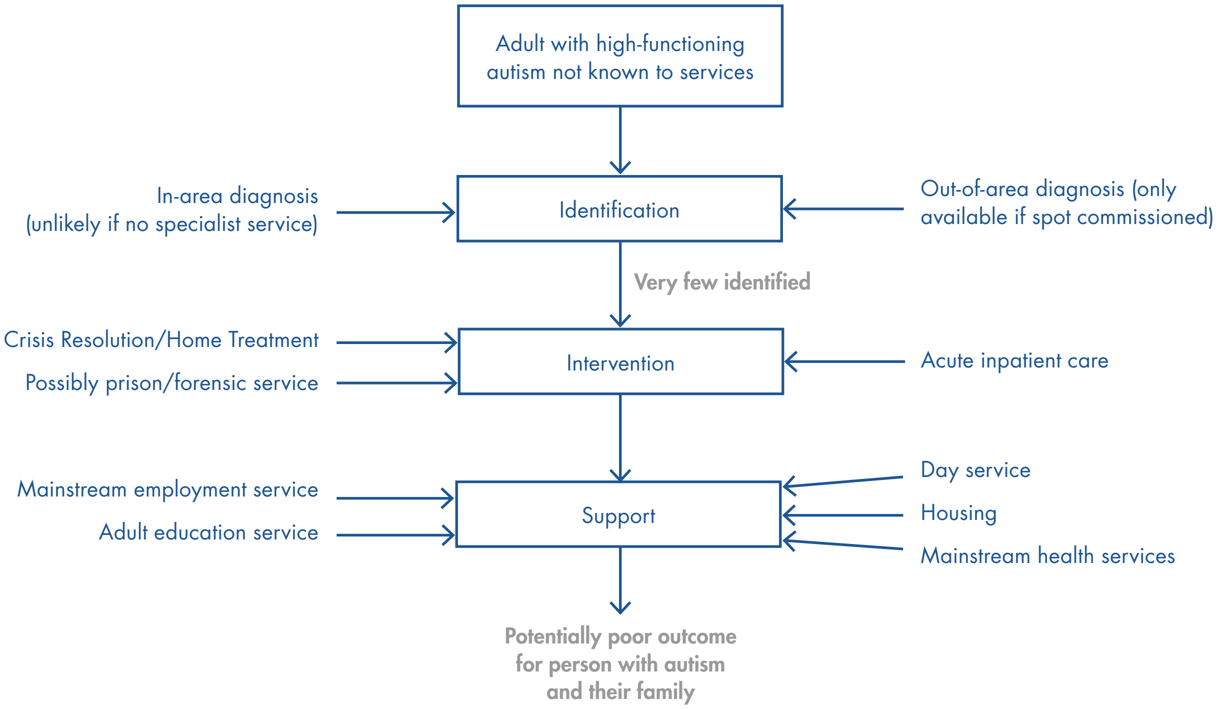
- costs to the NHS: inpatient care, crisis resolution/home treatment, NHS accommodation and treatment costs (including the NHS contribution to specialist autism services);
- costs to local government: social services costs (including contribution to specialist autism services), employment support (LA-funded provision), housing (in or out of area), adult education, day services;
- costs to central government: employment support (DWP-funded provision); and
- costs to private individuals: accommodation, family expenses, carers' lost earnings.

10 Decision tree model to compare the costs of current service provision against the cost of providing specialist Multi-Disciplinary Team (MDT) support for adults with high-functioning autism (HFA)



Source: National Audit Office

11 Care pathway and service utilisation with no specialist service in place

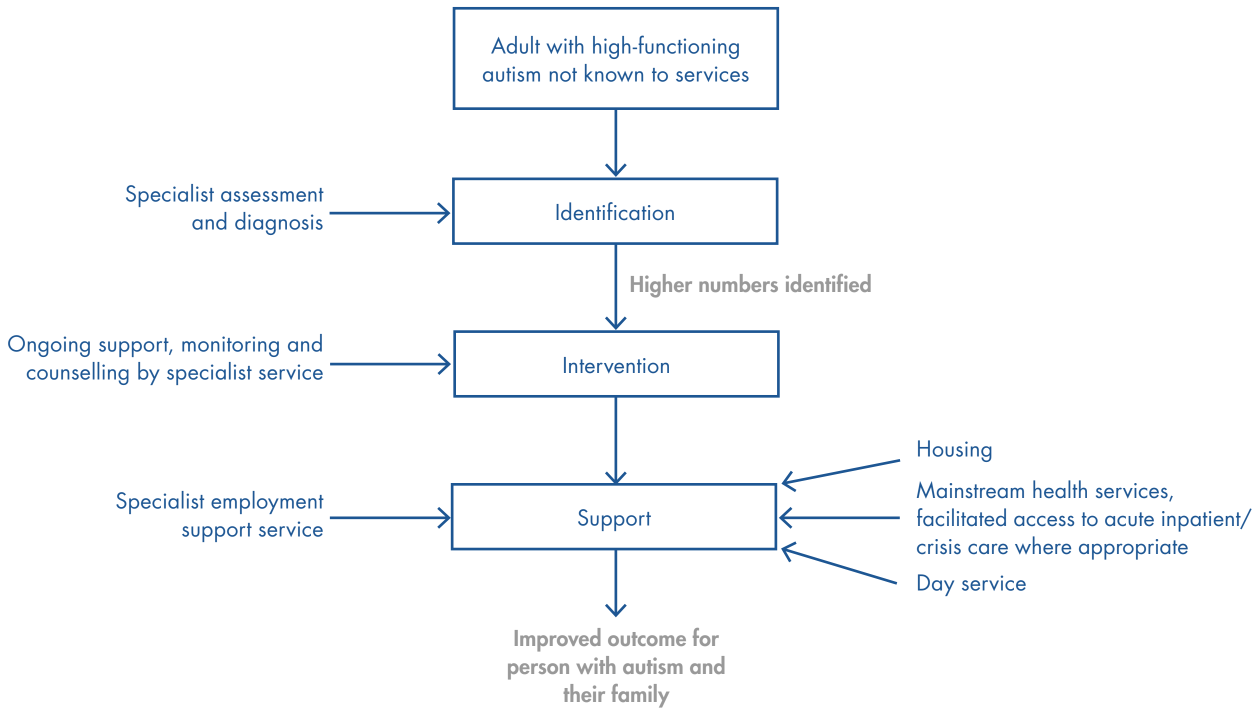


Source: National Audit Office

8 One of the intended outcomes of the specialist service is increased employment, which is desirable in itself, as well as potentially reducing benefits payments and increasing tax revenue. However, there is only limited data available to evaluate these effects. The Prospects study[70] showed that, on average, benefits claimed by adults with high-functioning autism in employment tend to go down, but that they could also go up if the specialist autism service identifies individuals eligible for, but not currently claiming, benefits. We have assumed that the benefits to the public purse from reductions in costs through decreased benefits payments due to increased employment rates, would be approximately one fifth of gross income earned. This is consistent with the evidence on the benefits accruing from disability employment support schemes more generally.[71] In respect of direct tax flowbacks from increased employment (tax and national insurance), we have not treated these as a benefit to the public purse, but have instead calculated increased earnings on a gross basis. Our base case employment assumption is that 18 per cent of adults with high-functioning autism are in employment, with two-thirds of these being in full-time employment,[72] although we consider alternative employment scenarios in the paper describing the model on the NAO website.

9 The cost of providing specialist autism services via a multi-disciplinary team is applied to the cohort of general population as a fixed cost, regardless of the level of identification, and at what stage on the patient pathway it is utilised. Full details on all costs used in the model, as well as the parameter ranges considered in sensitivity analyses, and the distributions fitted when modelling uncertainty in the estimates, are given in the description of the model on the website.

12 Care pathway and service utilisation with specialist service in place



Source: National Audit Office

---

[70] Howlin P, Alcock J, Burkin C, 'An 8 year follow-up of a specialist support employment service for high-ability adults with autism or Asperger syndrome' in *Autism* 9(5) (2005), 533-549.

[71] National Audit Office, *Gaining and retaining a job: the Department for Work and Pensions' support for disabled people*, p. 49 (http://www.nao.org.uk/publications/0506/gaining_and_retaining_a_job.aspx) (13 October 2005); Department for Work and Pensions, 'Equality impact assessment for "Helping people achieve their full potential: Improving specialist disability employment services"' (http://www.dwp.gov.uk/resourcecentre/equality-impact-assessment-isdes.pdf) (February 2009).

[72] Barnard, J, et. al., *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders* (National Autistic Society, 2001), p. 7 (http://www.nas.org.uk/content/1/c4/28/61/ignored.pdf).

Results

10 The analysis in the paper describing the model indicates that the modelled total cost is most sensitive to the prevalence estimate for high-functioning autism, followed by hospitalisation rate, and probability of residential care. The incremental cost of service utilisation with a multi-disciplinary support service in place for adults with high-functioning autism/Asperger Syndrome – in other words, the estimated financial impact of providing more specialised services – is sensitive to the proportion of the overall cohort of adults with high-functioning autism identified by services. Other key drivers of the incremental cost are employment rates and housing settings. These are examined further below.

11 To examine the joint effects of uncertainty in the values of the parameters to which the outputs of the model are most sensitive, these parameters were assigned probability distributions, and a so-called 'Monte Carlo' simulation was run, whereby each of these parameters is assigned a value sampled from its distribution and the results for incremental costs given by the model are calculated. After each sampling, the model is rerun, and the process is repeated 10,000 times to produce a distribution of possible results. The results indicate that, assuming the distributions for model parameters given in the accompanying paper on the NAO website, there is a greater than 99 per cent chance that providing a specialist service for adults with high-functioning autism will be cost saving once it is established and if eight per cent of adults with high-functioning autism are identified by the service.

12 In order to test the likely impact of different rates of identification of adults with high-functioning autism (as a proportion of the estimated prevalence within each Local Authority), we held the identification rate constant at various levels, and ran the simulations again.

13 **Figure 13 overleaf** shows that if an identification rate of about 14 per cent (the rate currently being achieved by the longest-running specialist Asperger service in England, the Liverpool Asperger team) could be achieved across the country, the estimated total benefit to the public purse could be £159 million (£5,000 per 1,000 working-age population). At a more conservative estimate of a realistically achievable identification rate of eight per cent, the model suggests the benefit could be £67 million per annum.

14 These figures depend, however, on a number of key assumptions, and more good-quality data is needed to quantify the potential costs and benefits more precisely. For example, potential savings are sensitive to the probabilities of adults with autism being in residential and supported housing settings before and after specialist services are in place, and also to the overall rate of employment of adults with high-functioning autism, and to the efficacy of specialist employment support services in increasing the probability of being in employment.

15 Further sensitivity analyses on these parameters are considered in the technical paper on the NAO website.

Conclusion

16 Clearly, the financial impacts of providing specialist services for adults with high-functioning autism/Asperger Syndrome depend on many factors. Our modelling work was designed to examine the impacts that would be likely to occur under a range of plausible scenarios, using the best available information from a wide range of sources to inform the costs and probabilities on which such estimates depend.

17 The modelling suggests that providing a specialist service for adults with high-functioning autism/Asperger Syndrome is unlikely to be cost-increasing. 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 over time become cost-neutral for overall public expenditure, as well as resulting in additional earnings and reduced expenses for individuals.

18 Increasing the identification rate further could result in greater financial benefits, potentially creating net savings over time. For example, our indicative results suggest 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. However, these figures depend on a number of key assumptions, some of which we have had to base on the limited data currently available. Better information, for example regarding housing settings and employment rates, is needed to quantify the potential costs and benefits more precisely. We therefore recommend that the Department of Health, in partnership with other government departments and local bodies, use our modelling as a basis to explore in more detail the potential impacts of implementing such services.

13 Probabilistic Sensitivity Analysis with identification rate held constant at various levels, showing England-wide costs and benefits to both public services and private individuals

	Annual England-wide incremental costs/(benefits), specialist service vs no specialist service						
Identification rate	**2%**	**4%**	**6%**	**8%**	**10%**	**12%**	**14%**
Estimated cost/ (benefit) to Department for Work and Pensions (£ million)	0.0	3.2	6.4	9.5	9.5	12.7	15.9
	0.0-3.2	0.0-9.5	0.0-12.7	0.0-15.9	0.0-22.3	3.2-25.4	3.2-28.6
Estimated cost/(benefit) to Local Authorities (£ million)	0.0	(35.0)	(70.0)	(104.9)	(139.9)	(174.9)	(209.9)
	(22.3)-15.9	(95.4)-3.2	(165.4)-(6.4)	(241.7)-(19.1)	(311.6)-(28.6)	(381.6)-(41.3)	(448.4)-50.9
Estimated cost/(benefit) to NHS (£ million)	22.3	25.4	25.4	28.6	31.8	31.8	35.0
	22.3-22.3	22.3-28.6	22.3-31.8	22.3-38.2	25.4-41.3	25.4-47.7	25.4-50.9
Estimated total cost/ (benefit) to public purse (£ million)	**22.3**	**(6.4)**	**(38.2)**	**(66.8)**	**(98.6)**	**(130.4)**	**(159.0)**
	6.4-38.2	**(57.2)-28.6**	**(127.2)-19.1**	**(190.8)-6.4**	**(251.2)-(3.2)**	**(314.8)-(9.5)**	**(381.6)-(19.1)**
Estimated total cost/ (benefit) to private individuals (including gross earnings) (£ million)	**(6.4)**	**(6.4)**	**(9.5)**	**(12.7)**	**(15.9)**	**(19.1)**	**(22.3)**
	(9.5)-0.0	**(15.9)-(3.2)**	**(22.3)-(3.2)**	**(28.6)-(3.2)**	**(35.0)-(6.4)**	**(41.3)-(6.4)**	**(47.7)-(6.4)**
Estimated Income Tax and National Insurance contributions recovered from benefits to private individuals but not counted as benefits to public purse, above (£ million)	(1.59)	(3.18)	(4.77)	(6.36)	(7.95)	(9.54)	(11.13)
	(3.2)-0.0	(6.4)-0.0	(9.5)-(1.6)	(12.7)-(3.2)	(15.9)-(3.2)	(19.1)-(3.2)	(22.3)-(3.2)

Source: National Audit Office

NOTE

Figures may not sum exactly due to rounding. Figures in grey are 95 per cent confidence intervals for the estimated results.

Limitations of the model

19 Based on existing data, this model suggests that providing specialist multi-disciplinary support to adults with high-functioning autism could be marginally cost saving, and that these savings would increase considerably if the identification rates achieved by established services could be replicated across the country. However, a number of assumptions in the model are deliberately conservative to acknowledge that the evidence underpinning them is currently limited, and that further research is needed to produce more robust estimates. For example, as well as the uncertainties around parameter estimates outlined above, the model does not currently take into account potential savings from avoiding inappropriate interactions with the criminal justice system. Although the research base to date is very limited, expert opinion suggests that high-functioning autism and Asperger Syndrome may be disproportionately represented among the prison population, and that a proportion of these detentions could potentially have been avoided through appropriate early intervention and case management.

20 Similarly, although the best available data were used to model the probability of clients accessing inpatient and crisis resolution treatment before and after coming under the care of the specialist service, it is possible that interactions with these services prior to diagnosis were not recorded as consistently in that period as in the period after diagnosis, where local services were aware of the service user owing to contact with the team. One possible result of this is an understatement of NHS acute care costs incurred by adults with high-functioning autism prior to diagnosis. This is in turn could lead to a potential overstatement of incremental costs to the NHS once such people come under the care of the specialist service, and their interactions with acute services (and hence the associated costs) are more accurately recorded.

21 Another limitation is that, although the model uses the best available information about the relative costs of different types of housing setting, this evidence base remains limited, particularly as very few Local Authorities were able to give us figures for how much they spent on accommodation for adults with autism. Linked to this, it is difficult to estimate the implications for housing benefit payments resulting from more adults with high-functioning autism living independently. Whilst estimated reductions in housing benefit are included in the estimate of benefits avoided as a result of increased employment in the model, there may be increases in housing benefit for people not receiving significant employment income but nonetheless living more independently. This might have some effect on the attribution of total costs and benefits to private individuals and public organisations, and more research would be useful to explore in more detail the implications of this for both Local Authority and DWP budgets. Also, the model does not explore whether care is provided in- or out-of-area. Implementing our recommendation that all Local Authorities and NHS partners review their out-of-area placements for people with autism would provide further evidence on this topic, and allow a more robust estimate of the savings that might be realised through a specialist local support service.

22 It should be noted that our aim in building the model was to explore the extent to which there is scope for value-for-money improvements in service provision for adults with high-functioning autism. The model is therefore a snapshot rather than a detailed year-on-year cost-benefit appraisal based on timed and discounted cashflows. Expenses such as training costs (both qualification and autism-specific training) are apportioned to the multi-disciplinary team on an annuitised basis in the model, and hence are recognised as an annual expense rather than a front-loaded investment. Similarly, we have made no attempt to monetise quality-of-life improvements for adults with autism or their carers, but have concentrated solely on financial costs and benefits to the public purse and to individuals.

GLOSSARY

Access to Work	A Department for Work and Pensions disabled employment support scheme which provides individuals who are in paid work or self-employed and employers with advice and information, and also offers a grant towards any extra costs.
Acute services/care	Acute services treat episodes of serious illness with a rapid onset and relatively short duration (as opposed to ‘chronic’ illnesses, which have indefinite duration).
Asperger Syndrome	A form of high-functioning autism (q.v.). Although people with Asperger Syndrome do not have problems with language or cognitive development, they experience the same difficulties with social interaction and communication associated with other types of autism.
Attendance Allowance	A non-means-tested Department for Work and Pensions benefit which can be claimed by individuals aged 65 and over who need help with personal care or need watching over.
Attention-deficit/hyperactivity disorder (ADHD)	A neurobehavioral developmental (q.v.) disorder, whose symptoms usually present before the age of seven. It is characterised by a persistent pattern of impulsiveness and inattention, with or without a component of hyperactivity.
Autism	A lifelong developmental disability (q.v.) which impairs social interaction and communication, and can also produce restricted and repetitive behaviour. The main difficulties 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.
Autistic Spectrum Condition (ASC)	See ‘autism’.
Autistic Spectrum Disorder (ASD)	See ‘autism’.
Carer’s Allowance	A taxable benefit for people who look after someone who is disabled. To be eligible for Carer's Allowance, people need to be aged 16 or over and spend at least 35 hours a week caring for a person getting Attendance Allowance, or Disability Living Allowance (q.v.) at the middle or highest rate for personal care, or Constant Attendance Allowance (at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, or basic (full day) rate with a War Disablement Pension). Carer's Allowance is not available for people in full-time education with 21 hours or more a week of supervised study, or earning more than £95 a week.

Carer's Assessment	An assessment, carried out by a social worker or a member of social services, which enables an unpaid carer to discuss with social services the help they need to care, to maintain their own health and to balance caring with their life, work and family commitments. Social services use the assessment to decide what help to provide and cannot refuse to meet an identified need solely on the basis of funding. They may, however, set eligibility thresholds according to the availability of resources (see also Fair Access to Care Services).
'Classic' autism	A form of autism which, in addition to social impairments and restricted behaviours, also involves associated learning disability (sometimes defined as having an I.Q. below 70) and language delay.
Commission for Social Care Inspection (CSCI)	The official regulator for adult social care in England, which until 31 March 2009 registered, inspected and reported on adult social care services and councils who provide and commission these services. CSCI was replaced by the Care Quality Commission on 1 April 2009.
Community Mental Health Team (CMHT)	A multi-disciplinary team offering specialist assessment, treatment and non-acute care to people in the community.
Complex needs	A range of multiple and additional needs that some people with learning disabilities may have. It includes people with profound and multiple disabilities and people whose behaviour presents a challenge. The definition includes people with difficulties related to autism. The conceptualisation is similar to that of challenging behaviour, which is also used to refer to people with more moderate learning disabilities in conjunction with a diagnosis of autism.
Connexions	A Government-funded service for children and young people in England, which through multi-agency working aims to provide young people with information, advice and guidance (including on careers). It is intended to give them access to personal development opportunities to help remove barriers to learning and progression, and ensure they make a smooth transition to adulthood and working life. Connexions is designed to help all young people aged 13-19 regardless of need, and those aged up to 25 with a learning difficulty or disability. From 1 April 2008, the funding that previously went directly to 47 Connexions Partnerships now goes directly to all 152 Local Authorities (q.v.).
Crisis Resolution and Home Treatment (CRHT) team	A service aimed at treating adults with severe mental health difficulties in the least restrictive environment and with minimum disruption to their lives. It acts as a "gatekeeper" for admission to acute mental health services, and where appropriate provides intensive multi-disciplinary treatment at the service user's home.
Day Care	Care provided during working hours at centres to which service users travel or are transported.
Decision Maker (DWP)	Department for Work and Pensions officials who make decisions about claims and applications on behalf of the Secretary of State. Decisions are made on the basis of completed claim forms and supporting information and evidence.
Developmental Disability	A cognitive, emotional, or physical impairment that manifests itself in infancy or childhood and involves a failure or delay in progressing through the normal developmental stages of childhood. Autism (q.v.) is a form of developmental disability.
Director of Adult Social Services (DASS)	A Director in every Local Authority (q.v.) with responsibility for ensuring high quality, responsive adult social services, promoting well-being and ensuring better integration of adult social services with a range of partner agencies in the local community.

Disability Employment Advisor (DEA)	A specialist Personal Advisor (q.v.) attached to one or more Jobcentre Plus offices and providing specialist support on employment issues both for disabled people currently in work and for disabled people looking for a job.
Disability Living Allowance (DLA)	A non-means-tested Department for Work and Pensions benefit which can be claimed by individuals under 65 who need help with a personal care or getting around. Claimants may be in work or unemployed. It comprises a care component and a mobility component, either or both of which may be claimed.
Disabled Person's Tax Credit	Disabled Person's Tax Credit can be claimed by individuals in work but disadvantaged because of illness or disability. Amount awarded depends on savings.
Disabled Students' Allowances (DSA)	A grant now administered by Student Finance England, which helps meet the extra course costs students can face as a direct result of a disability or specific learning difficulty. They are aimed at helping disabled people to study on an equal basis with other students. Eligible full-time, part-time and postgraduate students can apply for Disabled Students' Allowances.
Early Intervention (EI) service	Early intervention services provide treatment in the community for young people with psychosis, seeking to improve their long-term health and well-being by early diagnosis and treatment.
Employers' Forum on Disability	An employers' organisation focused on disability as it affects business. It aims to enable companies to become disability confident by making it easier to recruit and retain disabled employees and to serve disabled customers.
Employment and Support Allowance (ESA)	A new Department for Work and Pensions allowance which focuses on capability for work rather than benefit entitlement or incapacity. After an initial assessment phase claimants are put on one of two components: 'Work-related' component – conditional on drawing up a personal action plan focused on rehabilitation and work-related activity – and 'Support' component – for those with the most severe illnesses and disabilities, who are not required to undertake work-related activity. Employment and Support Allowance (q.v.) replaced Incapacity Benefit (q.v.) from 27 October 2008.
Fair Access to Care Services (FACS)	A national set of eligibility criteria for adult social care services, introduced by the Department of Health in 2003. It is intended to establish individuals' levels of need and risk, and place them in one of four 'bands': 1 Critical – for example where an individual might be at high risk and their life might be in danger. 2 Substantial – for example where, without help, someone will be unable to live independently in their own home. 3 Moderate – for example where help is required to prevent someone becoming more dependent on other people. 4 Low – for example where someone is unable to carry out one or two personal care or domestic routines, but is not at great risk. An individual needs assessment (q.v.) is carried out by adult social care services to establish which band (if any) a person should be placed in. Councils are not obliged to fund care for people in all bands, however, and for example may choose to fund only those with critical and substantial needs.
Healthcare Commission	An independent body which until 31 March 2009 inspected the quality and value for money of healthcare and public health, equipped patients and the public with information about the provision of healthcare and promoted improvements in healthcare and public health. The Healthcare Commission was replaced by the Care Quality Commission on 1 April 2009.

‘High-functioning’ autism	A term used to refer to autism where no associated learning disability is present (usually defined as having an I.Q. of 70 or above).
Hospital Episode Statistics (HES)	An official dataset managed by the Information Centre (q.v.) containing details of all admissions to NHS hospitals in England.
Incapacity Benefit	Until 26 October 2008, a Department for Work and Pensions benefit which could be claimed by those who were previously in work but now incapable of work due to sickness or disability. Incapacity Benefit was replaced by Employment and Support Allowance (q.v.) from 27 October 2008.
Independent Living Funds (ILF)	The Independent Living Funds are open to applications from severely disabled people who meet their eligibility criteria and are permanent residents of the United Kingdom. They were set up as a national resource dedicated to the financial support of disabled people to enable them to choose to live in the community rather than in residential care. They provide a ”direct payment” that enables people to purchase care from an agency or pay the wages of a privately employed Personal Assistant (PA).
Individualised Learner Record (ILR)	A collection of data about learners and their learning that is requested from learning providers in the FE system by the Information Authority (q.v.). The data collected are used by organisations in the FE system to ensure that public money is being spent in line with government targets for quality and value-for-money, for future planning, and to make the case for the sector in seeking further funding.
Information Authority	An independent body which sets and regulates data and collection standards for all organisations involved in further education and training in England.
Information Centre (for Health and Social Care)	A special health authority responsible for providing data to help the NHS and social services run effectively.
Jobcentre Plus	An agency of the Department for Work and Pensions whose aim is to support people of working age from welfare into work, and help employers to fill their vacancies.
Job introduction Scheme (JIS)	A Department for Work and Pensions employment support scheme for those whose disability may affect the kind of work they can do. JIS pays a weekly grant to employers for the first six weeks of employment to help towards wages or other employment costs.
Jobseeker’s Allowance (JSA)	The main benefit for people of working age who are out of work, or working less than 16 hours a week on average. To be eligible for JSA, a person must be capable of working, available for work, actively seeking work and below state pension age.
Joint Strategic Needs Assessment (JSNA)	The Local Government and Public Involvement in Health Act 2007 requires Primary Care Trusts and Local Authorities to produce a Joint Strategic Needs Assessment (JSNA) of the health and well-being of their local community. JSNAs are intended to identify the health and wellbeing needs of the local population, and lead to more effective commissioning and service provision.
‘Kanner’ autism	See ‘classic’ autism.
Learning and Skills Council (LSC)	A non-departmental public body responsible for planning and funding education and training for everyone in England other than those in universities. Its main tasks are to raise participation and achievement by young people, increase adult demand for learning, raise skills levels, improve the quality of education and training delivery, equalise opportunities through better access to learning, and improve the effectiveness and efficiency of the sector.

Learning Difficulty	A broad term that covers a wide range of needs and problems, including behavioural problems and dyslexia, and the full range of ability. According to the Education Act 1996, a child has a learning difficulty if: (a) they have a significantly greater difficulty in learning than the majority of children their age, or; (b) they have a disability which either prevents or hinders them from making use of educational facilities of a kind generally provided for children of their age in schools within the area of the Local Authority; or (c) they are under the age of five and are, or would be if special educational provision were not made for them, likely to fall within (a) or (b) when of or over that age.
Learning Disability	The Children Act 2004 defines learning disability as 'a state of arrested or incomplete development of mind which induces significant impairment of intelligence and social functioning'. Health services generally define learning disability as an I.Q. of below 70.
Learning Disability Partnership Board (LDPB)	LDPBs are groups comprising members of local organisations and the wider community (including service providers, commissioners, people with learning disabilities and carers), whose aim is to implement the Department of Health's *Valuing People* (q.v.) strategy locally.
Local Authority (LA)	National policy is set by central government, but local councils are responsible for day-to-day services and local matters, including the provision of social care. There are 152 Local Authorities with Social Services Responsibilities in England, and they are funded by government grants, Council Tax and business rates.
'Low-functioning' autism	A term sometimes used to describe autism with an associated learning disability (usually defined as an I.Q. less than 70).
Mental Health Minimum Data Set (MHMDS)	A dataset managed by the Information Centre (q.v.) intended to cover adult (including elderly) service users in England receiving specialist mental health care. Since April 2003 all NHS providers have been required to maintain such a dataset. The independent sector is not currently mandated to provide data for the MHMDS, although from April 2009 a subset of the MHMDS will also be required from commissioned independent Mental Health care providers. MHMDS currently includes over 100 data items, including demographic information, information on care management, assessment information such as diagnosis, and details of care provided.
Mental Health Trust/Foundation Trust	NHS organisations providing specialist mental health services, commissioned by one or more Primary Care Trusts (q.v.).
National Institute for Health and Clinical Excellence (NICE)	An independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. It produces guidance in three key areas: ■ Public health guidance on the promotion of good health and the prevention of ill health. ■ Technology appraisals on the use of new and existing medicines and treatments within the NHS, and guidance evaluating the safety and efficacy of procedures used for diagnosis or treatment. ■ Clinical guidelines on the appropriate treatment and care of people with specific diseases and conditions.
Needs Assessment	Needs assessments are carried out by Local Authorities to establish the needs of an individual who requires help from local social care services and to arrange services to meet their needs. Local Authorities may set eligibility thresholds on the services they provide according to the availability of resources. (See also Fair Access to Care Services).

Not in Education, Employment or Training (NEET)	The Department for Children, Schools and Families sets definitions for full and part-time education and training, and uses these to calculate the number of people in a given age group not in education or training (NET) by subtracting the number known to be in education or training from the total population for the age group. The Labour Force Survey, which seeks information on employment status from residential households and nursing accommodation, is used to estimate what proportion of the residual NET group is NEET.
Out-of-area treatment/ placement	An inpatient admission or residential placement outside pre-arranged service agreements or geographical catchment areas, often owing to lack of local capacity. Out-of-area placements generally incur higher costs than treatments carried out locally under existing service agreements.
Personal Advisor (Connexions)	Connexions Personal Advisors are based in local Connexions offices, and provide information, advice and support for children and young people aged 13-19 or those with learning difficulties up to 25. Working in multi-disciplinary teams, they are intended to: provide high-quality information and advice; influence the quality and appropriateness of provision for young people; deliver personal development opportunities; provide advocacy and brokerage; link to other organisations; support young people in care and young offenders; carry out needs assessments, and develop and implement plans to meet the needs identified.
Personal Advisor (Jobcentre Plus)	Jobcentre Plus Personal Advisors are based in local Jobcentre Plus offices. Their role is to help people find and retain work by addressing the barriers they may have to employment, drawing upon support from a wide range of programmes. Personal Advisers carry out work-focused interviews (q.v.) with customers, to discuss and improve their prospects of obtaining work.
Personal Capability Assessment (PCA)	Prior to October 2008, the assessment process used to determine eligibility for Incapacity Benefit (q.v.). From October 2008, it has been replaced by the Work Capability Assessment (q.v.).
Person-centred Planning (PCP)	Person-centred planning involves designing care services which fit in with the needs of the individual and make changes accordingly. The Department of Health *Valuing People* strategy identifies five key features of person-centred planning: ■ The person is at the centre. ■ Family members and friends are full partners. ■ Person-centred planning reflects a person's capacities, what is important to that person, and specifies the support they require to make a valued contribution to the community. ■ Person-centred planning builds a shared commitment to action that will uphold a person's rights. ■ Person-centred planning leads to continual listening, learning and action, and helps a person to get what they want out of life.
Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)	A condition in which people display some (but not all) features of autism or another developmental disability (q.v.), such as impaired social interaction or obsessive interests.
Primary Care Trust (PCT)	The organisation responsible for planning and commissioning health services and improving the health of a local population. There are 152 Primary Care Trusts in England.
Public Service Agreement (PSA)	A document setting out government departments’ aims, objectives and performance targets, agreed between departments and the Treasury in Spending Reviews. Progress against PSA targets is reported each year in departmental reports.
Residential Accommodation	Accommodation providing full-time care to individuals who cannot be supported at home or in supported housing (q.v.).

School Action	School Action is additional or different support provided by a school when a pupil is identified as having Special Educational Needs (q.v.).
School Action Plus	School Action Plus is triggered when a pupil continues to make little or no progress despite having received extra support from the school through School Action (q.v.). It involves seeking advice or support from specialists outside the school.
Section 140 Assessment	Until 2008, Section 140 of the Learning and Skills Act (2000) required all pupils with a Statement of Special Educational Needs who were expected to go on to further or higher education or training to have a needs assessment (a 'Section 140 assessment'), to be carried out by Connexions in the final year of compulsory education. The Education and Skills Act (2008) transferred this responsibility from Connexions to Local Authorities, as well as giving them the power to arrange assessments for people with a learning difficulty but no Statement who are in their last year of compulsory schooling, or are over compulsory school age but under 25, and are receiving, or are likely to receive, post-16 education or training.
Social care	Services which support people in their day-to-day lives to help them play a full part in society. Services provided range from home care and nursing homes to the provision of a personal assistant for a disabled person, or support for an individual in emotional distress. Each of the 152 Local Authorities (q.v.) in England has a statutory duty to assess the social care needs of individuals and to arrange for the provision of appropriate services to address the needs of those who are considered eligible for support (see also Fair Access to Care Services).
Social Care Institute for Excellence (SCIE)	An independent charity funded by the Department of Health (q.v.) and the devolved administrations in Wales and Northern Ireland, whose aim is to identify and disseminate the knowledge base for good practice in all aspects of social care throughout the United Kingdom.
Special Educational Need (SEN)	The Education Act 1996 defines a pupil as having a Special Educational Need if he or she has 'a learning difficulty [q.v.] which calls for special educational provision to be made for him or her'. The Act imposes duties on schools and Local Authorities to identify, assess and meet children's Special Educational Needs. It places a duty on NHS organisations to assist Local Authorities where a child has Special Educational Needs.
Statement of Special Educational Needs (SEN Statement)	A statement of Special Educational Needs sets out in detail a pupil's Special Educational Needs, the provision required to meet those needs, and the type and name of school that the pupil should attend. A statement can only be made by a Local Authority, and only after a statutory assessment of the child's needs under section 323 of the Education Act 1996. Local Authorities have a duty to arrange the provision specified in the statement, and the governing body of a maintained school has a duty to admit the pupil if it is named in the statement. The statement must be reviewed at least every 12 months.
Strategic Health Authority (SHA)	The body responsible for performance-managing NHS organisations within its geographical region. There are 10 SHAs in England (28 prior to 1 July 2006).
Student Finance England	A service delivery partnership between the Student Loans Company, Local Authorities and the Department for Innovation, Universities and Skills, which administers student loans and grants.
Supported housing	A form of housing with staff support (on-site or visiting), for example shared houses with integrated support or grouped individual self-contained flats, with or without shared communal facilities.

Supporting People	*Supporting People* is a grant programme that funds housing-related support services, administered through Local Authorities (q.v.) in partnership with Housing, Health, Adult Social Care Services and Probation, and delivered largely by the third sector. *Supporting People's* main aim is to help end social exclusion and to enable vulnerable people to maintain a suitable and stable independent home within local communities through the provision of vital housing-related support. It aims to deliver high-quality cost-effective and strategically planned housing-related support services in order to meet local needs and priorities.
Universities and Colleges Admissions Service (UCAS)	The organisation responsible for managing applications to higher education courses in the UK.
Valuing People	A government strategy aimed at improving the lives of people with learning disabilities (q.v.), their families and carers. It focuses on the rights of people with learning disabilities, their inclusion in local communities, and giving them choice and independence in daily life.
Work Capability Assessment (WCA)	An assessment of an individual's capability exploring the effects an illness or disability has on their ability to work. It is made up of three parts and is intended to assess what someone is able to do, rather than simply what they cannot. The three parts are: ■ The 'assessment of limited capability for work', which aims to identify those individuals who currently have a limited capability for work, but who would benefit from assistance and support and health-related activity to maximise their full potential. ■ The 'assessment of limited capability for work-related activity', which identifies those customers with the most severe limitations arising from their illness or disability. These customers will become members of the 'Support Group' of Employment and Support Allowance (q.v.) and will not be expected to prepare for work, but may volunteer to do so. ■ The new 'work-focused health-related assessment', which provides the customer with access to a healthcare professional specifically to discuss their views about moving into work, and also identify any health-related interventions that may support this.
Work-focused Interview	Most people claiming Employment and Support Allowance (q.v.) will be expected to attend a series of Work-focused Interviews with their Personal Advisor (q.v.), discussing the package of support required to help them into work, assessing and improving their prospects of obtaining work and identifying training and work opportunities relevant to their needs and abilities.
Work Preparation	A Jobcentre Plus employment programme offering individually tailored support to anyone returning to work after a long period of sickness or unemployment. Programmes are normally available locally, either at the premises of a programme provider or a local workplace. Most people who take part use it for between six and 13 weeks.
Workstep	A Jobcentre Plus employment programme which provides tailored support to find and retain work for disabled people with complex barriers to finding and keeping work. It offers ongoing support to enable permanent employment in the open job market.

Printed in the UK for the Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office
6152796 06/09 65536