



House of Commons
Public Accounts Committee

Supporting people with autism through adulthood

Fiftieth Report of Session 2008–09

*Report, together with formal minutes, oral and
written evidence*

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The Public Accounts Committee

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Publication

The Reports and evidence of the Committee are published by The Stationery Office by Order of the House. All publications of the Committee (including press notices) are on the Internet at <http://www.parliament.uk/pac>. A list of Reports of the Committee in the present Session is at the back of this volume.

Committee staff

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Summary

Autism is a lifelong developmental disorder which affects the way people interact with the world around them. The three main areas of difficulty which all people with autism share relate to 'social communication', 'social interaction' and 'social imagination'. Some people with autism can live relatively independently, while others require a lifetime of specialist care. There are around 400,000 adults with autism in England, around half of whom have a learning disability (sometimes known as 'low-functioning' autism), while half do not ('high-functioning' autism, which includes Asperger Syndrome).

People with autism may require concerted, individualised support across health and social care, housing, education, and employment. However, local organisations do not currently have sufficient awareness of the number and needs of people with autism in their area, limiting their ability to plan effectively to provide services to this group. The transition of people with autism from children's to adult services is often poorly managed and requires more effective leadership and relationships between services.

The traditional configuration of health and social care services has meant that adults with high-functioning autism may fail to access appropriate support, potentially only doing so if they develop more serious problems later. These problems can be exacerbated by poor knowledge of autism amongst health and social care staff assessing the needs of people with autism and their carers.

Despite the fact that many people with autism have skills which could be valuable to employers, only around 15% of people with autism are in full-time employment. There is a lack of awareness and knowledge of autism among potential employers and Jobcentre Plus staff, which can result in poor decision-making and job outcomes for adults with autism.

The effectiveness of services for adults with autism could be improved by raising levels of knowledge and awareness amongst decision-makers and service providers. More specifically, there is scope to provide targeted services for adults with high-functioning autism, which could improve quality of life for people with autism and their carers, as well as potentially reducing costs to the public purse.

On the basis of a report by the Comptroller and Auditor General,¹ we took evidence from witnesses from the Department of Health, the Department for Children, Schools and Families, and the Department for Work and Pensions about developing a strategy and services for adults with autism, autism awareness and access to services, and improving the effectiveness of services of adults with autism.

1 C&AG's Report, *Supporting People with Autism through Adulthood*, HC (2008–09) 556

Conclusions and recommendations

1. **The Department of Health is currently developing an adult autism strategy for publication in 2010.** For this strategy to be effective, it should set out how each of the recommendations made in the Comptroller and Auditor General's Report will be implemented, including specific timeframes and indicators to measure progress and performance. The National Audit Office should revisit this topic in 2011 to review progress in implementing the strategy.
2. **Local organisations are not making effective use of existing information to plan and provide appropriate services to adults with autism and their carers.** To remedy this:
 - NHS bodies and Local Authorities should collate local learning disability and mental health data to identify and record all adults with autism known to services;
 - Local organisations should use Joint Strategic Needs Assessments to identify the needs of adults with autism in their area, and make greater use of pooled budgets and joint commissioning to develop and deliver effective, integrated services, and
 - Directors of Children's and Adult Services should work together, using routine Schools Census data, to identify future demand for adult services from pupils with autism and Special Educational Needs approaching school-leaving age.
3. **The transition of young people with autism from children's to adult services is currently not managed effectively.** The Connexions service is supposed to support young people through transition, but as at December 2008 Connexions did not know the training, employment or education status of 31% of its clients aged 16–24 with learning difficulty or disability. The Department for Children, Schools and Families should require Connexions services to provide complete and comparable data from the 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. The National Transition Support Team should use its local self-assessment work to identify and promote good practice in transition planning for young people with autism.
4. **Staff working in health, social care, benefits and employment services do not currently have sufficient knowledge and awareness of autism.** To remedy this:
 - Local Authorities should provide autism training to Connexions personal advisors and to all staff carrying out community care assessments;
 - The Department of Health should work with the Royal College of General Practitioners to develop autism content in the GP training curriculum, and provide guidance to Primary Care Trusts on how to improve knowledge of autism amongst existing GPs and primary care practitioners, and

- The Department for Work and Pensions should provide autism awareness training to all Disability Employment Advisors who have not yet received it, and make sure that all Jobcentre Plus staff are familiar with wider guidance on autism, developed in consultation with individuals and organisations with expertise in the condition.
5. **Adults with high-functioning autism often fail to gain access to appropriate diagnosis and support because no specialist services exist locally.** The Department of Health should build on the financial modelling in the C&AG's Report to show Local Authorities and NHS bodies the costs and benefits of specialist diagnostic and support services for high-functioning autism.
 6. **Out-of-area placements are not always based on appropriateness or clinical need, and can divert resources which could be used to develop more cost-effective services locally.** Local Authorities and NHS bodies should review the appropriateness and cost-effectiveness of their long-term out-of-area placements of people with autism. Strategic Health Authorities should review annually the extent of out-of-area provision commissioned by local bodies, benchmarking this against other regions.
 7. **Employment rates for people with autism are low, and existing supported employment provision does not always meet their needs.** The Department for Work and Pensions should:
 - examine the feasibility of collecting routine data on whether applicants for Jobseeker's Allowance and Employment and Support Allowance have a diagnosis of autism;
 - work with employer organisations to raise awareness of the benefits of employing people with autism, and the adjustments needed to support them, and
 - in developing contractual and funding arrangements for future supported employment programmes, acknowledge the specialist knowledge, relatively long-preparation times and ongoing support required to produce successful job outcomes for people with autism.
 8. **University students with autism may need to use Disabled Students' Allowances (DSAs) to fund social, rather than course-related, support.** The Department for Business, Innovation and Skills should make clear to DSA assessors and higher education disability advisors that support packages for students with autism can legitimately include social mentoring as well as course-related support.
 9. **The C&AG's Report has identified the need for government departments to work together when supporting groups with specialised or complex needs.** The NAO should carry out a further, more wide-ranging study to identify where barriers exist to closer joint working, at a national and local level, to deliver services for such groups, for example where costs are borne by one department but benefits fall elsewhere.

1 Developing a strategy and services for adults with autism

1. Adults with autism may require support across health and social care, housing, education, and employment. Health and social care services are traditionally configured to cater for people with learning disabilities (defined as having an I.Q. less than 70), physical illnesses or disabilities, or mental illness (which autism is not). Adults with high-functioning autism are often deemed ineligible for social care and mental health services, and may only access them if they develop more severe problems later.² 74% of Local Authority areas responding to the NAO survey said adults with autism who do not meet eligibility criteria experience or report difficulties accessing services they require.³

2. Local Authorities and NHS bodies are not currently reflecting autism in strategic planning, and there is a lack of robust data on the numbers, needs and living arrangements of adults with autism across the country.⁴ Only 18% of Local Authorities and NHS partners responding to the NAO survey were able to give precise numbers of adults with low-functioning autism known to services, while only 12% could do so for the high-functioning group.⁵ Lack of good information about the numbers and needs of adults with autism limits local organisations' ability to identify need, plan capacity and commission appropriate services.

3. Adult care services are currently being reconfigured with an emphasis on joined-up strategies and services. Local organisations have a statutory duty to produce Joint Strategic Needs Assessments (JSNAs) to inform operational plans and Local Area Agreements.⁶ While 92% of local areas responding to the NAO survey reported having a JSNA in place, only 21% of these said it included specific reference on the needs of adults with autism.⁷ Seventy-four per cent of respondents did not have a specific commissioning strategy for adults with autism.⁸

4. The Department of Health have committed to publishing an autism strategy no later than 1 April 2010.⁹ The Department for Children, Schools and Families and the Department for Work and Pensions have also committed to working closely with the Department of Health in implementing the autism strategy.¹⁰

5. The Autism Bill currently before Parliament requires the Department of Health to issue guidance to Local Authorities and NHS bodies on how they should implement the autism

2 C&AG's Report, para 3.1

3 C&AG's Report, para 3.3

4 Qq 83–86

5 C&AG's Report, para 1.10

6 Q 41

7 C&AG's Report, paras 1.12–1.14

8 Q 68; C&AG's Report, para 1.16

9 HL Deb, 10 July 2009, col 898

10 Qq 1–7

strategy.¹¹ Alongside this statutory guidance, the Department of Health also plans to publish specific guidance to support commissioners planning and providing services for adults with autism.¹²

6. Managing the transition of young people with autism from childhood to adult services requires effective planning, information sharing¹³ and joint working between health, social care,¹⁴ education and employment organisations. However, many Local Authorities have poor information on the Special Educational Needs and transition arrangements for children with autism in their area, even where such data is collected routinely (for example as part of the Schools Census). The Special Educational Needs code of practice requires every child with a Statement of Special Educational Needs to have a transition plan prepared in Year Nine of compulsory education, but only 45% of Local Authorities responding to the NAO survey said they knew how many children with autism and a Statement had a completed transition plan.¹⁵

7. The Connexions service supports young people with a learning difficulty or disability through transition and into further education, training and work up to the age of 25. However, the Department for Children, Schools and Families does not collect data consistently across Local Authorities regarding the proportion of over-19 year-olds with learning difficulties or disabilities not in education, employment or training, so there is a risk of Connexions losing sight of this group.¹⁶ As at December 2008, Connexions did not know the training, employment or education status of 31% of its clients aged 16–24 with a learning difficulty or disability.¹⁷ A recurring theme in the interviews and focus groups that the National Audit Office ran with transition managers and employment support providers was that transition support required more effective leadership and relationships between services, including employment support.¹⁸

8. The Autism Bill requires the Department of Health to issue guidance to Local Authorities and NHS bodies regarding planning and service provision for young people with autism during transition. The Department for Children, Schools and Families is currently one year into a three-year, £19 million Transition Support Programme, aimed at improving the experience of disabled young people and their families at transition.¹⁹

11 Q 33

12 Department of Health, *Services for adults with autistic spectrum conditions (ASC): Good practice advice for primary care trust and local authority commissioners*, (April 2009), p 7 (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097418)

13 Qq 76–79

14 Q 100

15 C&AG's Report, para 1.19

16 C&AG's Report, para 1.26

17 C&AG's Report, para 1.26

18 C&AG's Report, para 1.21

19 Q 60

2 Autism awareness and access to services

9. A key driver of whether adults with autism can access appropriate support is knowledge and awareness of the condition among those making decisions on eligibility or providing services. For example, people with high-functioning autism can appear articulate and able at first sight, yet may still require considerable support to cope with aspects of day-to-day life such as personal care.²⁰

10. GPs are likely to see a significant number of undiagnosed adults with autism each year, so need to be able to make appropriate onward referrals to diagnostic and support services. In addition, GPs will often be the main ongoing point of contact for patients with autism to access health and social care services, particularly in areas where specialist support is not available. However, 80% of GPs felt they required additional guidance and training to identify and manage patients with autism more effectively.²¹

11. Training provided to Local Authority staff carrying out needs assessments under Fair Access to Care Services (FACS)²² does not cover high-functioning autism in 70% of Local Authority areas responding to the NAO survey,²³ and a recent review by the Commission for Social Care Inspection found that assessments of need are often inadequate for people with autism.²⁴ The Department of Health is committed to issuing revised guidance to FACS assessors in Summer 2009, in which the assessment of people with autism (including high-functioning autism and Asperger Syndrome) will feature prominently.²⁵

12. Lack of understanding of autism amongst benefits assessors and medical services professionals informing decision-makers in the Department for Work and Pensions, also increases the risk of inadequate needs assessments, and hence incorrect decisions on eligibility.²⁶

13. A medical diagnosis is not usually necessary for adults to be eligible for services, since eligibility should be based on need rather than a diagnostic label. A diagnosis can nonetheless be helpful in informing assessments of a person's likely support needs, as well as preventing a misdiagnosis of mental illness or inappropriate contact with the criminal justice system.²⁷ Knowing that a person has autism can also be important in services such as Jobcentre Plus, where staff can access guidance on the needs of people with autism from

20 C&AG's Report, para 2.5

21 Q 30; C&AG's Report, paras 2.1–2.3

22 Fair Access to Care Services (FACS) is 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': Critical; Substantial; Moderate; or Low. Councils are not obliged to fund care for people in all bands and may, for example, choose to fund only those with critical and substantial needs

23 C&AG's Report, para 2.5

24 Commission for Social Care Inspection, *Cutting the cake fairly: CSCI review of eligibility criteria for social care*, (October 2008), p 4, (http://test.cqc.org.uk/_db/_documents/FACS_2008_03.pdf)

25 Q 23

26 C&AG's Report, paras 2.7–2.8

27 Q 44; C&AG's Report, para 3.7

trained staff or the intranet,²⁸ but are unlikely to do so unless they are aware that their client has the condition.

14. However, Local Authorities, NHS bodies, GPs and people with autism report a lack of specialist diagnostic services for adults with autism, and only 29% of Local Authorities and NHS bodies responding to the NAO survey commissioned specialist autism diagnostic services in 2007–08.²⁹

15. People with autism and their carers report a number of barriers to accessing benefits, including lack of awareness of the benefits to which they might be entitled, difficult application forms, the physical environment of Jobcentre Plus, and problems communicating their needs to Personal Advisors.³⁰ The Department for Work and Pensions' approach to supporting people with a disability through the benefits system is needs-based and not condition-specific.³¹ As a result, there is little autism-specific data available to explore take-up, expenditure or outcomes for benefit applicants with autism. From October 2008, however, the Department for Work and Pensions 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, decision-making and outcomes for this group.³²

16. While the overall employment rate for disabled people is 48%,³³ recent estimates suggest that only 15% of all people with autism are in full-time paid employment.³⁴ Other research suggests that only 12% of people with high-functioning autism are in full-time employment, and 6% part-time.³⁵

17. Jobcentre Plus Personal Advisors have access to online training modules covering autism, as well as the advice of Disability Employment Advisors (DEA) on specific disabilities. However, Personal Advisors may not be aware that their client has autism, for example if the client does not have a formal diagnosis, or does not declare their diagnosis, and hence may not seek advice from their DEA. Since November 2005, the Department for Work and Pensions has included autism-specific content as part of its training for new DEAs,³⁶ although a recent evaluation commissioned by the Department identified a lack of appropriate ongoing learning and development for those DEAs who have been in post for some time.³⁷

28 Qq 19, 45

29 Qq 25, 97, 102; C&AG's Report, paras 3.5–3.8

30 C&AG's Report, paras 3.34–3.39

31 Q 38

32 Q 35; C&AG's Report, paras 3.34–3.42

33 Office for National Statistics, *Labour Force Survey*, (2008)

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

35 Q 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>)

36 Q 39

37 Department for Work and Pensions, *Research Report No. 539: Disability Employment Advisor (DEA) Organisation in Jobcentre Plus*, (2008), (<http://www.research.dwp.gov.uk/asd/asd5/rports2007-2008/rrep539.pdf>)

18. The Government recently published *Valuing employment now*, a cross-government employment strategy for people with learning disabilities, which aims to close the gap between the employment rate for people with learning disabilities and that of the disabled population as a whole.³⁸ This strategy and its associated delivery plan include the provision of employment support for people who have both autism and a learning disability.³⁹

19. Some firms, such as BT, have pro-actively recruited people with autism as part of their diversity policy, creating a package of mentoring and reasonable adjustments to support these staff. They have worked closely with the National Autistic Society's 'Prospects' service to understand the nature of autism and identify jobs where their skills could be a particular advantage.⁴⁰

20. The Department for Work and Pensions acknowledges that people with autism can have valuable skills to offer employees, such as mathematical aptitude and great powers of concentration. Its recent *Employ Ability* programme seeks to educate employers about the potential benefits and obligations of employing staff with disabilities, including on-line case study material on Asperger Syndrome.⁴¹

21. Going to university can be a challenge for young people with autism, owing to the change of routine, location and social environment. Without appropriate support they may struggle to complete their course.⁴² Between 2003 and 2008, the number of applicants accepted to UK higher education courses with declared autism rose by 408%. Declaring autism does not in itself automatically entitle students to special financial support,⁴³ but university students with autism, as with other disabilities, can be eligible for Disabled Students' Allowances as determined by an objective needs assessment. 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'. Students with autism may need more support with the social side of university than with purely course-related matters, and Disabled Students' Allowances can also be used for this purpose, for example funding a social mentor. There is evidence, however, that Disabled Students' Allowances assessors and higher education disability advisors are not always aware that these allowances can be used to fund such social support.⁴⁴

38 The Social Exclusion Task Force, in partnership with the Department of Health and the Department for Work and Pensions, *Valuing Employment Now: Real Jobs For People With Learning Disabilities*, (24 June 2009), (http://www.cabinetoffice.gov.uk/media/217088/coi_real_jobs.pdf)

39 Qq 65–67

40 Q 52; C&AG's Report, Case Example 1, p 22

41 Q 105

42 C&AG's Report, para 3.30

43 Qq 93–96

44 C&AG's Report, para 3.33

3 Improving the effectiveness of services for adults with autism

22. In a few areas of the country, multi-disciplinary health and social care teams have been established for people with high-functioning autism.⁴⁵ Such teams can improve outcomes and quality of life for adults with autism by facilitating access to diagnosis, managing mental health problems, increasing the likelihood of employment and independent living,⁴⁶ and reducing the burden on carers.⁴⁷

23. NAO modelling of the potential costs and benefits of providing specialist health, social care and employment support more widely suggests that that, in addition to quality-of-life improvements for adults with autism and their carers, such services could also reduce costs to the public purse. This would be achieved, for example, by supporting people where appropriate to live in more independent and cost-effective housing rather than full-time residential care.

24. The NAO estimated that if such services identified and supported around 4% of the adults with high-functioning autism in their local area, they could become cost-neutral over time, as well as resulting in additional earnings and reduced expenses for individuals. Higher identification rates could increase these benefits further, potentially leading to net savings for the public purse.⁴⁸

25. To realise these potential benefits, however, local health and social care organisations and Jobcentre Plus would need to work together in developing services, for example through pooled health and social care budgets and joint commissioning arrangements.⁴⁹

26. Developing autism-specific expertise locally is also likely to reduce the need to send adults with autism to services outside the local area.⁵⁰ Recent research suggests that commissioning residential and inpatient services out-of-area can divert resources which could be used to develop services locally at lower cost, and that people with autism are more likely to be placed out-of-area than some other groups with learning difficulties.⁵¹

27. Lack of appropriate local housing provision for adults with autism was confirmed by the NAO survey, where 65% of Local Authorities and NHS bodies reported difficulty finding appropriate supported housing for people with autism in their local areas. 68% reported difficulty identifying appropriate residential placements within area.⁵² Moreover,

45 Q 46; C&AG's Report, paras 4.14–4.15

46 Q 80

47 C&AG's Report, paras 4.17–4.24

48 Qq 19, 46

49 Q 15; C&AG's Report, para 4.26

50 Qq 50, 51, 106

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>)

52 C&AG's Report, para 3.23

local organisations do not always have sufficient information about the placements they are commissioning out-of-area to gauge whether these are cost-effective and appropriate to need. 16% of local organisations responding to the NAO survey did not know how many adults with autism they were supporting out-of-area.⁵³

53 C&AG's Report, paras 3.15–3.16

Formal Minutes

Wednesday 15 July 2009

Members present:

Mr Edward Leigh, in the Chair

Keith Hill

Mr Don Touhig

Mr Austin Mitchell

Draft Report (*Supporting people with autism through adulthood*), proposed by the Chairman, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 27 read and agreed to.

Conclusions and recommendations read and agreed to.

Summary read and agreed to.

Resolved, That the Report be the Fiftieth Report of the Committee to the House.

Ordered, That the Chairman make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

[Adjourned till Wednesday 14 October at 3.30 pm]

Witnesses

Monday 15 June 2009

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Sir Hugh Taylor KCB, Permanent Secretary and **Mr David Behan CBE**, Director General for Social Care, Local Government and Care Partnerships, Department of Health, **Mr Hardip Begol**, Deputy Director for Special Educational Needs and Disability (SEND), Department for Children, Schools and Families, and **Ms Rebecca Sudworth**, Deputy Director, Disability and Work, Department for Work and Pensions

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List of written evidence

Department for Work and Pensions

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Oral evidence

Taken before the Committee of Public Accounts on Monday 15 June 2009

Members present

Mr Edward Leigh, in the Chair

Mr Richard Bacon
Angela Browning
Mr Ian Davidson
Nigel Griffiths

Mr Austin Mitchell
Dr John Pugh
Geraldine Smith
Mr Alan Williams

Mr Amyas Morse, Comptroller & Auditor General, **Mr Michael Whitehouse**, Assistant Auditor General, and **Mr Mark Davies**, National Audit Office, gave evidence.

Mr Marius Gallaher, Alternative Treasury Officer of Accounts, was in attendance.

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL

SUPPORTING PEOPLE WITH AUTISM THROUGH ADULTHOOD (HC 556)

Witnesses: **Sir Hugh Taylor KCB**, Permanent Secretary and **Mr David Behan CBE**, Director General for Social Care, Local Government and Care Partnerships, Department of Health, **Mr Hardip Begol**, Deputy Director for Special Educational Needs and Disability (SEND), Department for Children, Schools and Families, and **Ms Rebecca Sudworth**, Deputy Director, Disability and Work, Department for Work and Pensions, gave evidence.

Q1 Chairman: Welcome to the Committee of Public Accounts where today we are considering the Comptroller and Auditor General's Report on *Supporting People with Autism through Adulthood*, and we welcome from the Department of Health, Hugh Taylor, who is the Permanent Secretary. Perhaps I should congratulate you—Sir Hugh.

Sir Hugh Taylor: Thank you.

Q2 Chairman: Also David Behan, who is the Director General for Social Care for the Department of Health. From the Department of Work and Pensions, Rebecca Sudworth, who is the Deputy Director for Disability and Work, and from the Department of Children, Schools and Families, Hardip Begol, who is the Deputy Director for the Special Educational Needs and Disability Division. So we have three departments of state represented here. We treat this as a very important inquiry, a ground-breaking inquiry, which is entirely in line with the work that we have pioneered in recent years as a committee in encouraging departments of state to deal with conditions that have not perhaps had as much resource put into them as other conditions. So we are very grateful for all the work the National Audit Office has done for us. We are particularly grateful to Angela Browning, whose idea this was, a member of the Committee, and that is why we are having this hearing because of what Angela has done to make it happen, so we are very grateful to her as well. I will be asking her to ask a few questions in a moment because she knows a lot more about this than I do. This is a very good Report, Sir Hugh, is it not, and we have a strategy outlined in this Report—

I want this to be a positive hearing—I would like to ask each of the three departments, are you going to implement this strategy?

Sir Hugh Taylor: We very much welcome the NAO's Report. The Government has committed to publishing its own strategy on autism and as a result of the Bill that is currently going through the House it is likely there will be a legislative commitment to publish that strategy, and I think the contents of the NAO Report are pretty much foursquare with the kind of issues we will need to address in that strategy and in the subsequent guidelines.

Q3 Chairman: So the answer is yes?

Sir Hugh Taylor: The answer is yes.

Q4 Chairman: Thank you. Rebecca Sudworth?

Ms Sudworth: I would also like to say we welcome this very helpful and very important Report and the very positive recommendations that are in there and we will be working very closely with the Department of Health—

Q5 Chairman: You welcome the Report, are you going to implement the strategy?

Ms Sudworth: The National Autism strategy?

Q6 Chairman: In the Report we are discussing today, there is a strategy.

Ms Sudworth: Yes, we will.

Q7 Chairman: We are making very good progress here, we can go home soon. Are you going to implement this strategy outlined in this Report, Mr Begol?

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Mr Begol: Yes, we are working very closely with the Department—

Q8 Chairman: Thank you. That is a very good way to start the hearing. I would like to ask another question of all three witnesses, how many people with autism do you employ in your Departments?

Sir Hugh Taylor: The honest answer is, we do not know.

Q9 Chairman: Why do you not know?

Sir Hugh Taylor: Because we collect information relating to disability but we do not disaggregate that information at the moment. We do not ask people what form their disability takes. If I may speak personally for a moment, one of the things I have taken from reading this Report and looking at some of the interesting case studies which are mentioned here—and I am now speaking personally and not on behalf of the other departments—is that I think the Department of Health should be an exemplar in relation to the way we employ people with autism and I think we are, and I am going to take very seriously the business of making sure we do a lot better.

Q10 Chairman: The same question to Rebecca Sudworth. How many people with autism do you employ in your Department?

Ms Sudworth: We are in the same position as the Department of Health, in that we do not know. We ask staff whether they have a disability but we do not ask them the nature of that disability.

Q11 Chairman: How many people with autism do you employ, Mr Begol?

Mr Begol: A similar response to my colleagues. We do break down data by disability but those categories do not include autism.

Q12 Chairman: Do you not think, Sir Hugh—there is no point asking all these questions of all the witnesses—as we read in 2.16, that the lack of autism awareness is a major hurdle? Do you not think, if we were having this hearing in a year or two's time, and were taking this strategy forward, you might perhaps know this answer and be more aware of what was going on in your own workplace?

Sir Hugh Taylor: Yes.

Q13 Chairman: Anybody else want to comment on that? The answer is yes to that?

Sir Hugh Taylor: I should add, I also sit on a small group of Permanent Secretaries and other colleagues who look at diversity issues across the Civil Service, and one of the personal resolutions I have taken away from this exercise is to raise the whole question of awareness but also of action relating to our employment practices as government departments in relation to people with autism.

Q14 Chairman: Talking of that, if you look at 4.26 you will see it is made clear that the only way we are going to make progress is for the departments to work together. Do you think this is something your

Department and the other departments might make more progress on, put in more resources and ensure the various departments work together?

Sir Hugh Taylor: We are certainly committed to working together in handling the autism strategy to which the Government is committed. I think the issues raised in that part of the Report relate in particular to the way in which specialist services at local level might work together, might contribute to overall value for money at local level, and that is certainly one of the issues we want to take forward as we do some further work on cost benefit analysis and impact assessment and strategy.

Q15 Chairman: And working together means sharing resources as well, does it?

Sir Hugh Taylor: It can do. Certainly in relation to the learning disability services, for example, NHS bodies and local authorities operate pooled budgets in I think over 80% of areas at the moment, so I think you can work together, you can pool budgets, there is scope to do that and that is one of the issues we certainly want to explore as we take the strategy further.

Q16 Chairman: Rebecca Sudworth, obviously the third sector has a very important role to play in this, this is where the real opportunities can be created, what are you doing to maximise the effectiveness of their contribution and your help to the third sector to enable them to help?

Ms Sudworth: Absolutely, and in the DWP we recognise we cannot deliver our services without the engagement and support of the third sector, and we have a range of things we are doing to support the third sector in working with us to deliver those services, and that includes high level involvement in the design of our services, and the design of the way in which we commission our services. At a very practical level we provide a lot of support to smaller organisations who want to get involved in delivering our services. For example, in the recent events for both Flexible New Deal and the new Specialist Disability Employment Services, we arranged a series of workshops and presentations which were well attended by smaller and third sector organisations, where we explained in some detail the process of getting involved in delivering our services and also providing us with specialist support, and we commissioned some additional support to help smaller organisations who may be interested in forming special purpose vehicles or consortia to work together in that way. In fact I myself sat in on one of those sessions and it was a very helpful starting-from-the-beginning account of how to do that, so we know third sector organisations can require support and we have a range of ways in which we can do that.

Q17 Chairman: If we read this Report though, we see that before you can lecture the third sector, which you are perfectly entitled to do, you have to sort out the problem with your own staff and the lack of awareness amongst your own staff, have you not? This is dealt with in paragraphs 2.4 to 2.6, 2.11 to

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2.12. There is clearly a problem—and this applies to all the departments—and we are at the beginning of this strategy, so presumably you are going to tell me this is going to get a lot better.

Ms Sudworth: Would you like me to start with DWP first or make a general point?

Sir Hugh Taylor: In the consultation document which the Government has published on its strategy for adult autism, clearly one of the issues which it addresses and we need to address to follow that up, is awareness and training across all services with responsibilities for people with autism, and that ranges across the health service, local authorities and in organisations like DWP. So that is a generic issue which pretty well applies across the board. I think some organisations like DWP have already taken quite a lot of steps actually to give some of their advisers and others specific autism training. I think the Report itself brings out the fact that where that happens, the benefits to people with autism spectrum conditions are clear. The question really is about making sure that is comprehensive.

Q18 Chairman: Do you wish to comment on this, Mr Begol?

Mr Begol: We recognise the need to raise the awareness of the children's workforce in relation to autism. We have recently published the second phase of our inclusion development programme for those working in the early years plus those working in schools, to get that foundation level knowledge right. The material was prepared jointly, by working very closely with voluntary sector organisations, so the National Autistic Society and TreeHouse—Linda Redford from TreeHouse—who a few of you may know—sat on our steering group to check those materials, and they were very well received by the sector. The challenge of course is implementation. We can produce materials but we need to get out there and promote them—and getting people to take them up is a challenge.

Chairman: I had better stop there and allow Angela Browning to come in.

Q19 Angela Browning: Chairman, thank you very much. Before I begin I wonder if I could just draw the attention of all four of you to what I think is a very significant paragraph, and that is on page 49, paragraph 17, where it talks about the fact that providing specialist services for adults with high functioning autism and Asperger Syndrome is unlikely to be cost-increasing. In that paragraph it goes on to say how actually providing the right services would be not only cost-neutral but could result in it actually being a contribution to the Exchequer from taxation where people get jobs. I want all of you to hold that in your minds while I am asking the other questions. If I could begin with Rebecca Sudworth. Rebecca, I have over many, many years come many times to your Department to talk to officials and I have had a lot of experience of trying to get people with Asperger Syndrome particularly into paid employment. When you go into Jobcentre Plus, as I have done, sometimes with them, there is a lack of understanding among many

of the staff. Is there no possibility that within Jobcentre Plus you could have somebody who was peripatetic but who actually understood what you need to do, who could advise the other staff and perhaps set up monthly appointments going around different Jobcentre Plus's to be hands on in getting an individual into work?

Ms Sudworth: We do take that kind of team approach in working with our advisers, so an individual adviser does have a range of resources they can draw on. Obviously though the actual customer contact will depend on the benefits and services they are going to receive, but a personal adviser for example can draw on more specialist input from a disability employment adviser, and a disability employment adviser should be well placed either to offer some more specific input on the needs of a particular disability or, if they do not have the expertise themselves, they should know where to get that. For example, we have some comprehensive guidance on autism specifically available on our staff intranet which has been developed in partnership with stakeholders, and it includes a lot of detailed information about the kind of support that somebody with autism might need. So that guidance is there. Our staff can also draw on the input of work psychologists, who are also able to contribute, so everybody understands the particular needs that somebody with autism might have in making that journey through into employment. So I agree with you that that kind of team approach is very much what works in this sort of situation, and it is what we aim to do.

Q20 Angela Browning: There are some very practical things I would like to share with you today; really practical things. A lot of people with autism applying for jobs have not the opportunity to give references like other people, they may be very late in age coming into the work place and actually having to find references is difficult. Sitting through an interview on their own may be impossible. Are your staff geared up to ensure they are accompanied at the interview process if necessary in order to, if you like, translate, which they sometimes have to do, some of the rather more esoteric questions which are part of most companies' questions when they interview somebody for a job? I have not got time now to go into all the list but I would just say to you that your Department particularly has a heck of a long way to go. If you look at the Report from the NAO you will see on page 10, paragraph viii, it says that only 15% of people with autism are actually in paid employment. There is massive potential out there; a massive potential. Just bear in mind that first paragraph, how cost-neutral it would be if you put those appropriate resources into it, if you would. Can I come on now to health and social care. The Chairman asked all of you, do you talk and meet with each other. There is a difficulty with health and social care. On social care the way the assessment forms are formatted that social workers carry out to see if somebody qualifies for services, and the way individual local authorities have by definition to, if you like, eliminate people as much as bringing them

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into the fold, almost always eliminates people with Asperger Syndrome unless they are in some form of crisis. I would just ask you to look at. While they are the responsibility of social services for a while, if they do not get that social services support, they become a big charge to the Department of Health, all too often on mental health. Can I ask you first, Sir Hugh, what is your Department doing to ensure that particularly in psychiatric community services and particularly in the provinces away from the big centres of excellence people with autism get the appropriate mental health services?

Sir Hugh Taylor: Two steps. First of all, I think the points you have made about the assessment process are well made. I think in relation to mental health services for people with autism, which are very often consequential on their autism, and a failure sometimes to address the particular needs associated with their autism, it would be fair to say that provision there is, to be honest, patchy. So where there are very specific needs, for example, for forensic psychiatric support, I think it will be identified, where there is crisis, but I think, as this Report and other Reports have indicated, there are circumstances where people effectively end up in mental health services with mental health needs being addressed where actually what really needs to be taken on board are the problems associated with whether it is their Asperger Syndrome or whatever. People I have spoken to would acknowledge, I think, that within the psychiatric community there is sometimes a lack of understanding of the needs of people with Asperger. My basic position is that a lot of us are on a very steep learning curve in relation to this as an issue and it cuts right across services.

Q21 Angela Browning: I do lobby the Royal College of Psychiatrists on this. We have had some test cases through the courts. It is tragic when somebody with Asperger Syndrome, for example, is medicated for something they do not have, and your Department has the responsibility for that.

Sir Hugh Taylor: That is obviously one of the areas, and I think the Report brings this out well, where the potential benefits of more effective specialist services for people, particularly with Asperger Syndrome, would undoubtedly be felt and where those services do exist, there seems to be some evidence that people are kept out of mental health services or their demands on mental health services are reduced.

Q22 Angela Browning: Mr Behan, I do not know if you two share an office but I really wish you did because I am sure we would make a lot of progress if you did. Can I just ask you, coming back to this question of the assessment and services provided by Social Services, the IQ definition of a learning disability of 70 or under causes enormous problems to people on the autistic spectrum because even those with very high IQs can still have needs that will very often only be associated with somebody with a learning disability. It is that strangeness of the condition where you get these variations in ability in someone's life. Even this week I am writing to a local Social Services department who had excluded

somebody with Asperger's from having anything to do with them because this person has an IQ of over 70. For years I have had to send out leaflets both to health professionals and parents. What are you going to do about this? This is almost a way of denying people services by saying the rules say something else. That cannot be right, can it?

Mr Behan: I do work very closely with Sir Hugh. He is my boss and I am accountable to him.

Q23 Angela Browning: Perhaps you should not share the same office. I am sorry.

Mr Behan: It is a very nice office, I have to say. I will probably stop there. The significant point is the previous Minister did ask for a review of eligibility criteria and we asked CSCI, as the independent regulator at the time, to carry out a review. We asked them to pay particular attention to people with autism and people with Asperger's and through their inquiry they echoed in effect the sentiment behind your question. What we have committed to do later this summer is to publish some revised guidance around access to care services to ensure that the issue around people with both autism and learning disability and those people with Asperger's is prominent within that guidance. So in a sense the acknowledgement and recognition of the concerns that there are in the field will be brought forward in that guidance. The strategy itself: we are currently out for consultation on the strategy. We anticipate this is one of the key issues that we will address, particularly this issue around those people with Asperger's. A straight cut-off around IQ is not the best way to begin to deal with this. The whole ethos of our current policies in relation to health and social care are assessments which are much more personalised around individual need, and we think that individual budgets and the approach to personalisation is a much more appropriate way to address the particular needs of people with Asperger's, which is actually celebrating their difference rather than trying to deal with everybody in exactly the same way.

Q24 Angela Browning: I am delighted to hear that. I do hope it will filter down to practitioner level, because I have a feeling that when the Department of Health puts out guidance, it sits in somebody's filing cabinet and the practitioners on the ground still carry on using this arbitrary 70 IQ to deny services to people.

Mr Behan: We are clear that a policy will have an impact when people change the way that they are relating, not when we publish the policy. So a lot of effort will go into the delivery of the policy and we anticipate publishing alongside the strategy a delivery plan which will demonstrate to you, I hope, and to others how we intend to take this forward and actually begin to work with people to support their practice at a local level.

Angela Browning: Thank you. The Report does a great service to people by identifying the ongoing problems there are with diagnosis. They are mixed and varied, the problems with diagnosis. I have just

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been told I have had my ten minutes. I just want to make two quick points and maybe you will not have a chance to answer them.

Mr Bacon: Mr Mitchell just said to me maybe we should give you the whole hour.

Angela Browning: I am so sorry.

Chairman: You can certainly have some injury time.

Q25 Angela Browning: Thank you, Chairman. Can I just say on this point of diagnosis, diagnosis is flagged up. There are concerns about diagnosis and, again, it is out in the provinces. If you are fortunate enough to live in a big city with a specialism in your local hospital, people can diagnose. The area I am particularly concerned about—and I am not complacent about our child diagnosis; there has been a lot of progress in that area—is adult diagnosis. There are still a lot of people out there, some of them coming into middle age or even coming into old age, some of them needing elderly services now, the sort of people who live at home with mum and dad quietly all their life and never really get much attention from the statutory services. Sometimes, to diagnose an adult requires a really specialist diagnosis. Is there any way that we can make out-of-area diagnosis available for those more complex adult cases where really the expertise is not there in the local health service community?

Sir Hugh Taylor: In principle, I am sure the answer to that is yes, and I think it does happen in some areas.

Q26 Angela Browning: It is the funding of it that is the problem. It is where the money travels from to make that diagnosis possible.

Sir Hugh Taylor: Yes, funding is crucial and also, if I may say so, I think the powerful examples that are cited in the Report do demonstrate that there is a close link too between good diagnosis and the support package which is associated with that diagnosis. So that while I quite take the point that out-of-area diagnosis may well be helpful, you still need very close liaison, follow-up from that diagnosis to the care and support services.

Q27 Angela Browning: It is not something you can learn from a book.

Sir Hugh Taylor: It is not, and I am conscious that there are two or three effective means of carrying out diagnosis for people on the autistic spectrum, and one of the things we will certainly be doing in pursuing our strategy is looking to how we can expand and develop those services.

Angela Browning: Thank you, Chairman. The Committee has been very generous with me. May I just make two very brief points. The first is, can I thank the National Audit Office for what I think is an excellent Report, and all those who have co-operated with this Report. Also, as you know, I am retiring from Parliament when the election is called. This is, if you like, my swansong on autism. I shall not be here at the PAC when it convenes in a year's time but could I ask you, Chairman, through this Committee, to do what we have done with the Reports the NAO has sent us on stroke and

dementia, and that is to say, in my absence, would this Committee ask the gentlemen and ladies in front of us to come back in a year's time and report progress on this Report?

Mr Bacon: Hear, hear.

Chairman: I also will not be on this Committee in a year's time but the young whippersnappers like Mr Griffiths may still be here.

Q28 Nigel Griffiths: Thank you very much. This is an excellent Report but it is a damning indictment of the patchy nature of services across the board from local authorities, the health service and others, is it not?

Sir Hugh Taylor: I think it reflects the fact that this is an under-developed area where awareness has been rising but where still, as I have said in many cases, we are on a very steep learning curve, particularly in relation to adults with autism. The answer to your question is yes, it demonstrates that there is a long way to go.

Q29 Nigel Griffiths: It does highlight this terrific waste of human potential for those with high-functioning autism or Asperger Syndrome, that just ensuring that we identify and support them is likely to be cost-neutral and if we could boost our support to just touch 8% of these people, the saving would be some £60 million plus annually. Do you think you will be able to make a good case to the Treasury for extra resources?

Sir Hugh Taylor: I think there are two things. First of all, certainly the work the NAO have done on modelling this is very interesting and we want to pursue that further. I think they themselves recognise that there is more work to be done on it. We need to test some of the assumptions. It is a very powerful platform for us to hold discussions not just with the Treasury but with local authorities and PCTs and other fund holders. Obviously it is for Ministers in the end to decide collectively on priorities at national level but there is a lot of money out there at the moment and one of the questions is how you can prioritise resources effectively at local level as well. So I think the sort of modelling which is done here, which demonstrates that investment in one place can produce potential efficiency or productivity savings in another place is worth exploring.

Q30 Nigel Griffiths: Four out of five doctors say that they have inadequate training in autism to manage these very able patients of theirs. How are you committed to tackling that in the forthcoming strategy to stop, as Angela Browning said, it just lying in someone's in-tray?

Sir Hugh Taylor: We will certainly be talking to the Royal College of General Practitioners about this. I know that they are alert to this as an overall issue. I think they recognise that the current curriculum for GPs needs modification to make it more effectively tailored to addressing the needs of people with autistic spectrum conditions. They are actually about to launch in July of this year, I think it is, a new e-learning package for GPs and one of the things we

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will certainly be exploring with them is the scope for introducing more material in relation to people with ASCs into that sort of package.

Q31 Nigel Griffiths: That is welcome. Will you also introduce what is even more important and that is a way of monitoring the effectiveness of it?

Sir Hugh Taylor: Certainly, one of the things we want to do as we move this forward is to look at ways in which we can monitor the effectiveness of all the outcomes we are setting forward in our proposed strategy.

Q32 Nigel Griffiths: Having looked at them, will you then undertake to have the monitoring done effectively?

Sir Hugh Taylor: Yes.

Q33 Nigel Griffiths: Again, 71% of local authorities do not seem to have training for staff assessing the eligibility for care services for these two groups in particular. Again, how do you intend to rectify that to ensure that you are at 100% in the new strategy and the accompanying guidance?

Sir Hugh Taylor: I think essentially we need first of all to make it clear that our expectation is that there should be much higher levels of awareness and training among staff who may have responsibilities for people with autistic spectrum conditions but there has to be a process of engagement about that. Just sending out missives from the Department of Health is not in itself going to solve the problem. One of the things we are doing in relation to the strategy which Ministers have announced is having a targeted piece of engagement aimed not only at engaging people with ASCs themselves, their carers, their families and the people who support them in third sector organisations but local authorities, PCTs and others who work with them. We have to work together essentially to raise awareness of these issues, and that is one of the specific commitments in the autism strategy, that we will look at training and development for staff.

Q34 Nigel Griffiths: Ms Sudworth, is the DWP prepared to commit to monitor the number of people with autism claiming benefits such as Employment and Support Allowance and Jobseeker's Allowance?

Ms Sudworth: We are working to try and improve both the breadth and the depth of information we have on customers with a range of disabilities. What we can monitor depends obviously on the information collected and the accuracy of that information, and this will vary between different benefits. So just as one example, in Employment and Support Allowance we record the primary condition of customers who are claiming benefit using an international standard classification, and at the moment that could give us a proxy for the number of people with autism but it is still at quite a high level. It is, I believe, a category called pervasive developmental disorder, which does include people with autism but also includes some other customers.

Also, there are people who may have more than one disability and our systems are not very good at the moment at capturing that.

Q35 Nigel Griffiths: I think they are with the DLA too?

Ms Sudworth: That is right. I was pleased that in the Report you made mention of that recent improvement to Disability Living Allowance. So from autumn last year we are now able specifically within DLA to record both autism and Asperger Syndrome, yes.

Q36 Nigel Griffiths: The answer we are looking for is that what is happening now with DLA and continuing to happen will happen with ESA and JSA. Can you give us that commitment?

Ms Sudworth: We will keep this under review because obviously what is possible depends to some extent on—

Q37 Nigel Griffiths: That sounds like a “no”.

Ms Sudworth: It is not a “no” but obviously this depends to some extent on a range of different IT systems that we use, it depends on the source of that information, how we collect it, why we collect it, and that will be different across all of those different benefits. So what we are doing is, we are about to engage in a much closer dialogue with our stakeholders from a range of different disability groups just to look at both whether we are making the best use of the information that we do have and also the next improvements that we might want to make, looking across a range of different benefits and services and a range of different disability groups. We can deal with this as part of that, I very much hope.

Q38 Nigel Griffiths: But my concern is, if a Department cannot give that undertaking, we have no moral authority to tell local authorities, or indeed GPs, that we want to improve their awareness.

Ms Sudworth: For the services and benefits that we provide, we do not tend to use diagnosis or medical condition as the primary route of access. It is very important to understand the needs of customers with a disability and for a benefit like Employment and Support Allowance we do collect medical information and that is why we have a richer source of information that we can use to inform this. In other areas actually it is not necessarily so relevant to the service that they receive. What is more relevant is actually the need of the customer and their particular barrier to employment. We need to be very careful that we are not placing too much of a burden on our customers and our staff in collecting information that might not be relevant. We need to take this into account when we are thinking about how we can improve our information systems.

Q39 Nigel Griffiths: This Report says autism is part of the new Disability Employment Adviser training programme, and that there are 200 DEAs so far completing the programme. Does that mean they have all been trained in autism?

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Ms Sudworth: Autism is specifically part of the training that Disability Employment Advisers receive. My latest figures now are that 301 Disability Employment Advisers have received that training. The specific training is not the only way, as I mentioned before, that Disability Employment Advisers can inform themselves about the range of needs of customers with autism. They do also have access to the comprehensive, intranet-based guidance which all our staff can access and which contains a very comprehensive account of the sorts of things they might need to support them into work.

Q40 Nigel Griffiths: Mr Begol, the Report shows that only 25% of parents feel the transition support was co-ordinated. Of course, that is an absolutely critical time in these young people's lives. What measures do you think are going to emerge from the strategy that will improve communication between children and adult services during this transition?

Mr Begol: I think we recognise that transition is an extremely important issue. We recognised that in our *Aiming High for Disabled Children* report in May 2007. Since then we have invested in a transition support programme which is offering real practical support to local authorities to join up children and adult services on the ground, and I think over time what we want to see is those authorities that are doing well to actually push the boundaries forward and look at positive outcomes for children in their transition to adulthood, but for those authorities, of which there are far too many, where they are not working well together or not meeting their statutory duties, we help them to meet minimum standards. I think the support that the Council for Disabled Children and their partners, including the National Autistic Society, are providing is a way that transition will be improved over time.

Q41 Nigel Griffiths: Finally, Sir Hugh, there is a recommendation that PCTs, local authorities, should collate existing data from learning disability and mental health services so that they can identify and record adults with autism known to the services and that directors of children and adult services should forecast future demand for the services using that. Will you consider including these as statutory requirements?

Sir Hugh Taylor: We will certainly consider it. I think that sort of analysis should form part of the joint strategic needs assessment process which we have already set out. I recognise in the Report it is clear that it is not covering that effectively at the moment. What goes into the statutory guidance will in the end be a matter for Ministers to decide but certainly that is one of the factors we are looking at.

Q42 Mr Bacon: I should declare an interest here because my wife's brother has Asperger Syndrome. I have known him for five years and he has always worked during the time I have known him. In fact, he has worked his whole life. He has never not worked. Until the family moved recently to be nearer to us, he had a mortgage. My starting point on this was an assumption, completely wrong as it turned

out, that this was normal for somebody with Asperger Syndrome to be in work. I was very shocked when I first heard the statistic in the debate on the Autism Bill currently before Parliament, in February that it is only 15%. That did make me think, and Mr Griffiths was right when he said it is an indictment; this very good Report indeed is an indictment. Miss Sudworth, can you say what will Jobcentre Plus be doing in the next three to six months to make sure that there is better information to people on the ground about Asperger Syndrome and other autistic spectrum conditions and the employment possibilities for such people? I do not think that Jobcentres are really aware of this, even if you all are.

Ms Sudworth: Can I start by saying that I agree. We know that there are some groups whose employment rate is very low, and we absolutely agree that we must do something about that and it is very important that we do. Now that we have had a chance to have a first look at this very helpful Report, we are going to review the content of that training and guidance that I mentioned, which is the main guidance available to staff who need to inform themselves about the nature of autism and the kinds of support that people should be offered. I think that will be a good starting point.

Q43 Mr Bacon: How long will it take before people who work in Jobcentres know something about this that they currently do not know? That is really my question.

Ms Sudworth: I think we have come a long way. As Sir Hugh said, we are all on a learning curve here. We have improved our training over the past years and we continue to improve it. I think it is important to stress that we cannot expect all of our advisers to be expert in—

Q44 Mr Bacon: No, there is not a need for people to be expert. There really is not. Let me give you an example. The Essex Autistic Society, now merged with the Norfolk Autistic Society, recently came out with a card for people who have autism to carry in their wallet for the police. Sir Hugh is nodding. I think it is a National Autistic Society initiative that is now spreading around the country. As we all know, a lot of autistic people have difficulty looking people in the eye, so they naturally look shifty if they get into trouble with the police. You do not need to become an expert. A police officer has many things he has to think about but knowing this does not take expertise. I know, and I do not know a lot about this at all, that there are certain things you should not do to an autistic person. Trying to put them through a job interview is incredibly stressful; giving them a work trial is likely to show their true worth and that they have attributes which make them tremendously good workers. We are not talking about expertise. I go back to my initial question because I am not confident that you have answered it yet. What is going to happen in the next three to six months to make sure pretty much everyone working in Jobcentres knows something about this that they do not at the moment?

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Ms Sudworth: You are absolutely right that it is important that our advisers are equipped with the skills to deal with a whole range of customers, and there are other—

Q45 Mr Bacon: I am not asking about a whole range of customers. I am talking about people . . . With the greatest of respect, all I want is a simple answer to a relatively simple question, which is, what is going to happen in the next three to six months to make sure that people working in Jobcentres know something about this—not expert but know something about this that they currently do not know? This is my fourth opportunity to invite you to answer this question.

Ms Sudworth: What I have said is that we are going to review the training and guidance that is provided so that we are certain that all our staff have access to the best information about this. Our personal advisers receive a very comprehensive training which deals very precisely with some of the issues that you have been talking about. Many customers that come through the doors of Jobcentre Plus have a range of difficulties. You mentioned a particular communication difficulty that is relevant to someone with autism but there are many vulnerable customers who may have communication difficulties and who will find it, frankly, simply very difficult to talk to an adviser at that stage in their lives. Our adviser training covers that sort of listening skill, covers how to communicate with a range of customers who come with all kinds of different needs. They know where they can go if they require extra support, so they can draw on the more in-depth knowledge of Disability Employment Advisers. We have Incapacity Benefit Personal Advisers and we have Work Psychologists. There is a whole-team approach that we use which should equip all of our advisers to deal with that very wide range of customers, and we are going to review the specific autism content of that training with this Report in mind.

Q46 Mr Bacon: Sir Hugh, you said this Report is a very powerful platform to talk not just to Treasury but to others like local authorities, and I very much agree with you. The thing that strikes me, and I think you should all get it tattooed on your eyelids, is the point Mrs Browning made right at the beginning: this could save you money. If you look at the chart on page 50, it shows there in figure 13 that with an 8% identification rate, or, to put it another way, a 92% non-identification rate, the estimated benefit to the public purse is £66 million. Now, if Liverpool can manage a 14% identification rate—this chart only goes up to 14% and that is the maximum, so the maximum we are talking about here is an 86% non-identification rate you are saving £159 million. The fact that you are nodding suggests that you agree with me and I am sure you do. You also said this work does need its assumptions testing. The National Audit Office, who I have talked to about this, were explaining about the difficulty of getting information out of local authorities, and my own experience of mothers with adult sons with autism in

my own local authority—and I do not think it is a criticism of them particularly; it is universal—is the problem of falling between the stalls and they do not have the right information. So you do need to do more work and, helpfully, recommendation (x) of this Report says on page 10 “The Department of Health should build on our modelling”—that is the NAO’s modelling—“to show local authorities and NHS organisations the costs and benefits of specialised diagnostic and support services for high-functioning autism.” When are you going to build on their modelling and when will it be in a form that we can look at?

Sir Hugh Taylor: Almost immediately. The Government is committed to producing a strategy on autism to a timetable which is effectively established by the Bill which is going through the House at the moment. That will include both a delivery plan and an impact assessment, which will certainly need to look at the cost benefits associated with the various measures in the strategy. We will need to work on that with both PCTs and local authorities—there is no point in doing this without talking to them about it—and indeed to other partners across government. That work is a continuum really, building on the work the NAO have done, which we will want to take forward. I do not want to in any way denigrate from the work that has been done but it is important to recognise what this represents, which is always challenging—let us be honest—to individual government departments and separate delivery bodies, it is an overall value for money figure which presumes investment in one area to lead to potential productivity and efficiency savings in another. Nobody around this table is going to say that that is not exactly the right sort of thing we should be looking at and pursuing across government and across local authorities but, speaking in this particular Committee as an Accounting Officer, I have to recognise that effectively, what this Report recommends is that, as the Accounting Officer for health, I should invest in health services in this area. I accept there will almost certainly be benefits if that is what happens—

Q47 Mr Bacon: But they will not accrue to you. They will accrue to you as a citizen and as a taxpayer but they will not accrue to you as an accounting officer. That is the point you make.

Sir Hugh Taylor: They will in this sense: if they lead to benefits for the users of the service, for people with autism, and that is what in the end of course this is about. I am not trying to dodge that. All I am saying is that that is the sort of judgement which quite often government departments and local authorities and PCTs have not always found it easy to make. Our job, working with our colleagues across government, is to try to make it easier.

Q48 Mr Bacon: What you are going to need is joint working with very clear lines of responsibility.

Sir Hugh Taylor: Yes.

Q49 Mr Bacon: Is that what you are planning to try and deliver?

Sir Hugh Taylor: It is.

Q50 Mr Bacon: That is an answer. I am running out of time and the Chairman is very good shutting me up. I just want to ask you one more thing about out-of-area placements. You said something very interesting, which was that a lot of money is out there at the moment. I have discovered recently that my own local authority is spending a lot of money sending people out of area. Of course, the services out of area are often more complex than the light-touch, low-intensity regime—which is actually more appropriate in many cases—that could be provided in area. What are your plans to do something about that—again, it will save money—to get through to local authorities that they can do more with better outcomes than they are doing at the moment, and possibly with less money?

Sir Hugh Taylor: This is potentially local authorities and PCTs actually.

Q51 Mr Bacon: I meant both.

Sir Hugh Taylor: The answer is we have committed already, once we have done a consultation on the strategy, to put out some straightforward, practical—I know it is a horrible expression—toolkit guidelines for commissioners which points up good practice in this area. In fact, in the good practice guidance we put out as recently as April we surfaced this is an issue for local authority and PCT commissioners. Just one word of warning. I know that people with autism and their carers are warning us to be careful we do not throw the baby out with the bathwater on this, because there may be circumstances in which out-of-area placements are necessary but, certainly on the basis of this Report, and indeed our own knowledge of what is happening out there, we think this is an area where local authorities and PCTs could tighten up with benefit. Actually, I think one of the results of doing that will be that they will create better local facilities which will then be of benefit to a wider group of people within their own areas. So it is certainly an area to pursue.

Q52 Mr Bacon: One extremely brief question. Will you go and talk to British Telecom about what they do about employment for people with autistic spectrum conditions?

Sir Hugh Taylor: I thought it was excellent. I was genuinely, as a person, impressed with what they were doing. In particular this idea of a passport which people carry around with them I thought was a really excellent idea.

Q53 Mr Bacon: You could learn a lot from them and spread it around.

Sir Hugh Taylor: I hold my hand up to it. I think it is very good.

Q54 Mr Mitchell: This is an excellent Report. It is surprising that so little has been done. Why is that? The basic problem seems to be lack of information: lack of information about the numbers, lack of information about how these people need to be

helped, lack of information and education of civil servants and GPs. Why is this at this late stage in the game? I remember when I was first elected, a long time ago, there was an enormous problem in getting Humberside County Council, RIP, to actually recognise that there was something called autism and that it needed special treatment in schools. Is it a product of that kind of mentality?

Sir Hugh Taylor: I think it is important to remember that awareness—and I mean in an academic and service provision sense—of the needs of people with autism has been growing exponentially over recent years and that much of the focus, as it grew, was initially on children rather than adults, and I think that is the legacy that we are dealing with here. I am speaking not out of a huge depth of knowledge myself, to be frank, but my recollection is that Asperger Syndrome, for example, was only recognised in the international classification of disease in the mid-1990s. So we are talking about a relatively late developing area of knowledge. As awareness has grown, it has given to a lot of people, both as individuals, people on the autistic spectrum and people in services, explanations for things. So I think knowledge has been growing and there has been a lack of focus on autism in adults. Let us be clear. What we have seen, and what this Report demonstrates is a combination of the relative lack of focus on autism in adults and the way information is being collected, which has largely related to particular client groups, like people with disability, people with mental health—

Q55 Mr Mitchell: It seems surprising that many of them do not know how many people are affected in their area. Why is there not a national study which tells them how many people in each area are affected? Why are they not required to carry out their own study?

Sir Hugh Taylor: We are doing a number of things about this. We are commissioning research for a national prevalence study, which will give us better information, not just nationally but also on a disaggregated basis about expected prevalence.

Q56 Mr Mitchell: Area by area?

Sir Hugh Taylor: Yes. Expected. That will be a model. We are also using something—again, excuse the jargon—called an observatory, which we are setting up partly to look at getting better information on learning disability but extending that now to autism. So nationally we are trying to put more investment into finding better information but the key in the end is going to be, as the Report makes clear, for local authorities and PCTs to interrogate the services for which they are responsible to find out more.

Q57 Mr Mitchell: It also makes clear that the lack of information is the basic problem. Why cannot kids be tracked from school? If you have statemented kids, why can you not track them out of the system into adulthood?

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Sir Hugh Taylor: In principle they should be.

Q58 Mr Mitchell: Are they?

Sir Hugh Taylor: They are, but what the Report demonstrates is that there is not at the moment good enough joining up of information between the old Connexions service and the local authority providers of care and support for people with autism. So that is one of the fundamental issues we have to address as part of our strategy.

Q59 Mr Mitchell: It also says that only 29% of parents thought transition support was coordinated only 45% of local authorities that responded to the survey said they knew how many children with autism with a Statement of Special Educational Needs had a completed transition plan. So the transition looks pretty chaotic.

Mr Begol: It is not really good enough at all and that is why we have prioritised improving transition, sending out advisers to sit with authorities and actually address this issue. There are lots of authorities doing this well and I agree with you that adults with autism do not just turn up; they were children, they were young people, they went through transition, and that information does need to be passed on. We have seen in the education system that just in four years the proportion of children identified as having autism has gone up 50% and I think that is going to feed through; every four or five years we are going to be seeing an increase.

Q60 Mr Mitchell: As part of the new arrangements—and we are all full of good intentions—we want positive commitments. Will you commit to ensuring that adequate transition arrangements are in place in local authorities?

Mr Begol: Our aim is that by 2011 every single local area in the country is passing that information over, that they have arrangements in place where they are meeting the duties and the guidance that we have put in place.

Q61 Mr Mitchell: That is what I wanted to hear. There is also a source of information in GPs, yet I see paragraph 1.11 says that only one in five GPs reported that they kept registers of patients with autism, only 12% said they kept registers of all patients with autism, and 6% kept registers of patients with high-functioning autism. Why is that?

Sir Hugh Taylor: I think first of all, as we have already indicated, the level of training and awareness of GPs in relation to people with autism is, by their own admission, limited, and that is something which we will be addressing, as I said to the Committee earlier.

Q62 Mr Mitchell: Are you saying that GPs are not competent in the diagnosing?

Sir Hugh Taylor: I think competent is not the word I would use, but they are not formally trained in the diagnosis of autism conditions. As with many other areas, what they would expect to do, and I think the Report itself makes this clear, is wherever possible make referrals to specialists in the diagnosis of

people with autism. It is in that area, as already indicated, that we need to make further progress. The best form of diagnostic is a multidisciplinary team which links diagnosis to—

Q63 Mr Mitchell: Can you not require GPs to keep the registers?

Sir Hugh Taylor: Through our information centre, which looks at data collected from GPs, one of the things we are doing specifically is looking to make sure we have better—in technical jargon—coding methodology to see that GPs do this.

Q64 Mr Mitchell: Unless the information is mobilised, regularised and made available to local authorities it is not much use, however codified.

Sir Hugh Taylor: I think the key to this in many ways will lie both with people with autism who have learning disabilities and also people with Asperger Syndrome to get the services who are responding to their needs to identify them. That is the most likely way of getting improved information, although GP information will reinforce that as well.

Q65 Mr Mitchell: The learning disability employment strategy, which I would have thought was a very central document—

Sir Hugh Taylor: Yes, it is.

Q66 Mr Mitchell: --- does not seem to include autism, yet it springs from Public Service Agreement 16 which says that it should be included. Why is it not?

Sir Hugh Taylor: The delivery plan for the Government's learning disability strategy, *Valuing People Now*, certainly has autism as a key dimension of it and we will only really make services better for people with autism who have a learning disability if we absolutely mainstream it through the *Valuing People Now* delivery plan.

Q67 Mr Mitchell: But it is not in the strategy.

Sir Hugh Taylor: It is in the strategy.

Mr Behan: The employment strategy for people with learning disabilities, which is due to be published later this summer, will include the provision of employment services for those people with learning disabilities who also have autism as part of their presenting condition. The employment rate of people with learning disabilities is about 10% and the strategy's ambition is to push that up closer to the average that exists for those people with disability in the general population. It is a strategy which will focus on people with learning disabilities and autism. It is PSA16, the employment strategy, which is very specific on pushing the improvement of employment prospects for those people with learning disabilities and mental health and that does not specifically target autism.

Q68 Mr Mitchell: Why do 74% of local authorities not have a commissioning strategy for adult autism?

Sir Hugh Taylor: The answer is I think increasingly we expect them to have such a strategy.

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Q69 Mr Mitchell: Are you going to push them into having one?

Sir Hugh Taylor: We are. What we want them to do is to carry out a joint strategic needs assessment with their PCTs which will address the needs of people with autistic spectrum conditions. Effectively, that is a strategy which is both for local authorities and PCTs. Indeed, in the guidance we issued in April we reminded both local authority and PCT commissioners of the need to address this as central to their commissioning function.

Q70 Dr Pugh: I wonder if you can assist me first of all. In the Report I came across a statement that adults with high-functioning autism/Asperger Syndrome often struggle to obtain a diagnosis. I asked Angela on my right exactly what high-functioning autism was like. Am I right in assuming that it would be coupled with reasonable linguistic skills, mathematical skills?

Sir Hugh Taylor: Yes.

Q71 Dr Pugh: Is it also coupled with an ability to cope in a social context?

Sir Hugh Taylor: It can be, yes.

Q72 Dr Pugh: If that is the case we have got to find out how many people with high-functioning autism are actually in employment. Do we know that?

Sir Hugh Taylor: I do not think we do know exactly that figure. First of all, we have not got absolutely reliable information about how many people with Asperger Syndrome there are in the population. There are estimates of that. On the basis of some research that has been done, as already indicated, the suggestion is that only 15% of people with autistic spectrum conditions are in employment. It follows from that that a fair percentage of people with Asperger Syndrome are not in employment, but we do not have absolute figures.

Q73 Dr Pugh: It would be a useful fact to know really because we may be looking at a reasonable cohort of people who are within the spectrum but who are functioning in society as well as many of us are really.

Sir Hugh Taylor: What there is evidence of, and I think it is brought out in the Report, is where there are specialist services for people with Asperger Syndrome who are not in employment they can be supported back into employment. There are some very positive pointers in that.

Q74 Dr Pugh: Suppose I was high-functioning on the autistic spectrum and holding down a job, say as a physics lecturer or mathematics lecturer or something like that, what would I actually need?

Sir Hugh Taylor: You may need reasonable adjustments in your place of work. One of the things I have learnt, frankly, as a result of doing this and taken home, is the fact that quite often the sorts of conditions which are now common practice amongst employers, which is open plan, heavy strip lighting, people working very closely alongside each other, are quite difficult environments for people on the

autistic spectrum to cope with, so employers may need to make reasonable adjustments to take account of that.

Q75 Dr Pugh: Is there an issue of those people actually accepting that they have a diagnosis? I know certain people who have had difficulties with employment by being perversely stubborn about things that really are not important and clearly are one of the manifestations sometimes of Asperger or autism. My perception is that those people would not welcome a note being made in some cases on their employment record.

Sir Hugh Taylor: It would always be up to the individual as to whether they declared a disability; it would not be a requirement on them. The question is, can it be helpful? Where a disability is registered it is our duty as an employer to make any necessary reasonable adjustments to support those people in work. The challenge to us is where there are people who have this particular form of autism and it is obviously in their interests and in society's interests if they are in work and supported to be in work otherwise, on a worst case, they may need housing support, they may get other benefits and allowances, and in some cases problems associated with their condition will lead to depression and other forms of mental illness. It is a question of working proactively with people. As I understand it, and sorry to give you a long response to your question, while a lot of people with a disability, particularly with a mental health disability, often reject the label of that, the evidence is that people with Asperger and other forms of autism have often found the diagnosis helpful both in explaining the nature of their own condition to themselves and then for the purposes of having an open discussion with employers and others about the kind of support that might be helpful to them.

Q76 Dr Pugh: Following on from Mr Mitchell's line of questioning, we come across the fact in the Report that the doctors are not very good at diagnosing autism but clearly most of the adults now of working age will have had such an assessment made of them when they were at school. I know there is a reduction in the number of statements and so on, but at some point in time on a school record there was a statement that they were autistic, their parents identified them as autistic and they were given special provision by the school. Why should that simply not transfer to their medical records? The information is there in childhood, adolescence and so on but disappears at some point, does it not?

Sir Hugh Taylor: I am not sure.

Q77 Dr Pugh: If it is useful for doctors to know, why—

Mr Behan: The transition plan will pick this up. The driver around transition, particularly transition at 14, and the preparation for transition is designed to ensure that intelligence that is held by children's services will transfer. Going back to your question—

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Q78 Dr Pugh: Can I just stop you there. You are not going to suddenly become autistic or change from being autistic to something else, it is more or less a permanent lifelong condition. If it is identified in childhood and it is a known fact about an individual, what is the case against putting it on people's medical records?

Mr Behan: The earlier point that this only became a recognised classification in 1994 means that for adults who were born before 1994, so if you were born in 1955 as in my case and suffered from this, I do not think somebody with Asperger's would have been working as a lecturer, for instance, because they would not have been able to deal with that sort of situation, but they might have been a computer programmer quite happily in an office working away. The issue, therefore, is whether that would have been recognised and supported, which is why diagnosis in adults is important so that reasonable adjustments can be made by employers.

Q79 Dr Pugh: I agree, but you still have not told me or reassured me that the information that is known to the educational system is transferred across to the health sector.

Sir Hugh Taylor: In principle, I cannot see any reason why local authorities would not share information that would benefit the young person. I am sure that would be a matter of discussion with the individual concerned and their parents and carers.

Q80 Dr Pugh: Can I test the major assumption of the Report and that is that there are pots and pots of money that can be saved in one way or another through implementing some of the strategies recommended for better identification and so on. The Liverpool Asperger Syndrome Team has been mentioned as an example of good practice. I was looking for examples of good practice instead of theoretical figures coming out of thin air, I wanted to see where it was working and what was happening. Can you tell me how many people who have been through the Liverpool Asperger Syndrome Team have been helped into independent living?

Sir Hugh Taylor: I do not have that number off the top of my head, no. I know it has been cited as a good example.

Q81 Dr Pugh: Is it a good example not in the sense it picks up lots of people but in the sense it makes those people more capable of independent living?

Sir Hugh Taylor: Yes. If you dig down into the bowels of the piece of modelling work that the NAO have done, which I did go through at one stage during this process but I have not held that all in my head, what they have done is draw evidence from local authorities and PCTs, and that would include the Liverpool example, that they have adduced of just exactly that kind of benefit. We want to test those sorts of assumptions further.

Q82 Dr Pugh: What I read about the Liverpool experience was they were very good at identifying people and very good at finding services for people who had not hitherto been identified as having the

conditions they had, but I did not see the evidence in there that as a result of what they had done these people were helped into more independent living and, therefore, became more functional adults generally.

Sir Hugh Taylor: We could try and provide you with some more information on that. I recognise this is very limited exposure to these debates, but what I would say is I think it is clear from their own experience, and the team that do that in Liverpool are part of a mental health trust, they have seen benefits in terms of reductions in the amount of support needed on wider mental health conditions of people they have helped. Leaving aside other issues like employment and housing, there have been benefits there.

Q83 Dr Pugh: Of the number of people with adult autism, can you tell me how many of them are living with relatives as dependants?

Sir Hugh Taylor: I do not have that information.

Q84 Dr Pugh: Do you know how many are living in residential accommodation?

Sir Hugh Taylor: I am afraid I do not have that information either.

Q85 Dr Pugh: Do you know how many people diagnosed with Asperger or autism, apart from the high-functioning ones, are enjoying something we might call independent living?

Sir Hugh Taylor: We do not have that information in aggregate form. That is one of the reasons why we are doing the prevalence study that we are doing. As you can see, the evidence from this Report is the amount of information we have from local authorities and PCTs would not give us that sort of information.

Q86 Dr Pugh: My general perception is you do not know a great deal about the picture of adult autism really.

Sir Hugh Taylor: We accept that. The whole point of launching this strategy on the back of a Report like this is to say there is a lot we do not know about this and there is certainly a lot we do not know about the benefits associated with some of the programmes here. What I do not think anybody really disputes is that this is an issue which for good reasons has come right up the political agenda.

Q87 Dr Pugh: You must therefore infer that some of their financial savings through implementing some of the recommendations remain a little on the speculative side.

Sir Hugh Taylor: I think that is recognised by the NAO. Speaking as an Accounting Officer, I would certainly want to follow through on those very carefully.

Q88 Mr Davidson: I wonder if I could start asking about the scale of under-diagnosis. I think the point Mr Begol made earlier on was you said a whole range of people were being diagnosed now in schools who had not previously been picked up. Can I ask

about the social class background of those who have not been previously identified. Is this something that is predominantly picked up by what could be described as pushy middle class parents?

Mr Begol: We have looked at the take-up of free school meals, which is an indicator we use around social background and disadvantage, of every category of children with special educational needs. In every category you are more likely to be on free school meals than a non-special educational needs child, so there are no categories where it is a middle class issue. Autism is at the higher end in terms of affluence, but every single category is disadvantaged compared to other people. There are no “middle class” impairments.

Q89 Mr Davidson: In terms of identification, and clearly as with so many things it pays to pick your parents wisely, does it not, to what extent does the social background assist with diagnosis and getting services? Is there any evidence that there is a whole section of the community, as it were, who are too poor to have autism because it is simply not picked up?

Mr Begol: I think there is an issue around social background and outcomes from the education system and we have recognised that as a Department. One of our key goals through Public Service Agreement 11 is to narrow the gap in outcomes between children from disadvantaged backgrounds and their peers. There is that gap and we need to address it. That gap finds its way into lots of public services so I do not think it is anything to do with this area in particular. People who push and fight for services, which is often what parents of children with special educational needs say they have got to do, will achieve different levels of engagement with services.

Sir Hugh Taylor: There is a pervasive issue of health inequalities across the spectrum so I would be surprised if it was not manifested here, although we do not have any concrete evidence to demonstrate it. As we take forward the strategy to which the Government is committed, one of the dimensions we want to do as we are consulting is look specifically at whether there are particular groups in society who suffer from inequalities generally who may also be suffering disproportionately in relation to autism.

Q90 Mr Davidson: Could I turn to pages 28 and 29 where we have got maps of relative difficulties of finding accommodation and so on. In both of those it seems to be difficult in both cases. To what extent would you have the same map with the same preponderance of difficulty if you were examining a map that gave us appropriate residential accommodation, say, for the physically handicapped? Is this lack of accommodation unique to autism sufferers or is it just replicating the failings of the system for everyone?

Sir Hugh Taylor: I think it is difficult to judge that. I suspect it is probably pretty generic although I would need to take some further advice on that.

Q91 Mr Davidson: That is helpful. It would be my view that the accommodation situation, whether it is supported, residential and so on, is pretty bad across the board, so it is not unique to autism. Can I ask in terms of the costs and benefits of putting resources into autism and getting people back into work, given that financial resources are difficult, are short and likely to become shorter, how do the gains compare, say, dealing with people with alcohol problems, for example, if you are trying to get them into employment in terms of the amount you have to put in to get a certain amount back? Is this much more rewarding or much less rewarding, leaving aside the moral question, just in terms of the finance of it all?

Sir Hugh Taylor: I simply do not think we have enough evidence to answer that question properly. It is a good question in the sense that it is precisely the sort of question that local authorities and PCTs ought to be asking themselves when they make their own local decisions on prioritisation, just as we should be doing nationally. The key to is to make the decision on better evidence than we are able to do at the moment and that is really what this Report is pressing us to do.

Q92 Mr Davidson: I was not clear that the Report was saying that. I thought the Report was essentially saying here is an area where not enough is being done, more needs to be done, without looking at it in the wider context of the choices and priorities that you have to make.

Sir Hugh Taylor: We certainly have to do that. The thrust of the Report is that this is a category of people who very often at the moment are slipping through the net for one reason or another. This Report makes out a good case for investment to support them, but it is certainly a group of people who at the moment arguably local authorities and PCTs and other agencies are not looking at sufficiently in relation to other potential priority areas. Effectively, the NAO and the PAC have shone a light on an important area for us. Of course, I have to acknowledge that in the end decisions on priorities are a matter for ministers nationally and for local authorities and PCTs locally.

Q93 Mr Davidson: I wonder if I could just turn to the chart on page 30 about the numbers of accepted university applicants declaring they have autism. That is an interesting word and I am not quite sure of the significance of “declaring” they have autism as distinct from being diagnosed with. This seems to suggest it is something you can do yourself, as it were. Is the rise in those who declare themselves as having autism simply because more are being diagnosed, more are self-diagnosing? Would many of these people have gone to university anyway, even though they had autism? I can understand at the extreme end that some people would not be able to do it, but mild forms might very well have not made much difference.

Sir Hugh Taylor: This is well outside my Department’s area of expertise, but I think what we can say is this is a relatively small number of people on the autistic spectrum who go through to

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universities and, of those who do, this will be a self-declaration quite often based on a diagnosis as they have been through the transition support which we have been talking about. Its potential objective is to enable them to get some support to facilitate their way through university and there are some quite powerful examples given here of the kind of support that individuals can have which mean that they are able to get through what otherwise might be a difficulty.

Q94 Mr Davidson: I understand that, but I am never entirely certain that taking one or two examples which might be at the extreme is indicative of the overall picture. I am not sure all of the 800 or so would be as severe as, say, those in case example 3. I am not quite clear exactly what that is telling us. Maybe the NAO can help us with that in some way. Is this a question simply that more people have been diagnosed who would have gone to university anyway and, therefore, the figures have gone up? Has it been the case that they have been diagnosed at school and have had advantages and support at school that they would not have otherwise had which has enabled them to go forward?

Mr Davies: Basically they were undiagnosed. The numbers of people with a diagnosis have gone up in recent years, so that is part of the reason why numbers have gone up. It is also fair to say from the evidence in the Report that compared with some other parts of the public service, the support environment in higher and further education is actually better relative to some other parts of the public service with better support and better information.

Q95 Mr Davidson: You cannot tell that from this, of course, because you do not know how many of those who went in came out.

Sir Hugh Taylor: You would not know from this how many people might anyway have gone to university. The importance of this is now more people than before have had usually some form of diagnosis or support on the way which means that there is probably a better chance of them getting support through university. It is suggestive rather than demonstrative evidence.

Q96 Mr Davidson: In terms of being able to go to university and getting the grades and so on, does being identified or self-identified as having autism give you any advantages in working your way through the examination system?

Sir Hugh Taylor: It may have because universities, like any other employers, have duties in respect of people who declare disability. We all have those duties. One of our duties under legislation if somebody has declared a disability is we would have to make reasonable adjustments to support that. There are some examples of how that is done at university. I am not expert in this but there may well be particular things that can help an individual either in the context of the way their examinations are conducted or more particularly with the environment in which they are working.

Q97 Geraldine Smith: I think the Health Service does really well when you break your wrist or something; it is obvious, they know what to do and it is easy. The Royal Lancaster Infirmary did a brilliant job. Having said that, with autism it is not simple and I think that is one of the problems. Over the years I have realised that it is so wide-ranging and it has always struck me that people who seem to know most about it are the parents or relatives of adult children. They could have degrees in the subject because they go into such detail, but nobody ever seems to listen to them. I have had so many people who do not seem to be taken seriously. At the moment I have got one parent who has gone private to get a diagnosis because she needed the specialist who would know exactly what was going on because she had some knowledge and information, yet the National Health Service would not even refund the money that she spent getting that diagnosis because they disagreed with it because obviously people do not like admitting they are wrong. I have got another case of a parent with an adult child who is actually in a mental institution and this woman is quite convinced that her daughter does not suffer from a mental illness. It is very, very hard when you are fighting against professionals. What David said earlier is quite right, autism in 1994 was relatively new and we are still on a learning curve. We should listen to the people who are closest to those suffering from autism to take some account of what they are saying. This Report is excellent, but what assurances can you give me that the practical workings of it will be implemented at a local level so that we will begin to see differences in how people are treated.

Sir Hugh Taylor: First of all, building on your point, one of the key ways to ensure that this gets followed through is to keep listening to the experience of people with autism themselves and their families and carers. We have used very much their input through the external reference group that we put together of people whose lives have been touched by autism, whether professionally or personally, to develop the consultation on the autism strategy which we have done. One of the lessons we learned on the *Valuing People Now* delivery package was to make sure that alongside a proper group at senior departmental level, at regional level, in addition to the people who are responsible for the policy and delivery on this, like David and myself, we involve people who are users of the services and their carers and families. Keeping that voice going is absolutely crucial.

Q98 Geraldine Smith: That is not always the experience of people on the ground.

Sir Hugh Taylor: No, it is not.

Q99 Geraldine Smith: I met with a group of parents on Friday and the main concerns they had were, first of all, a lack of any sort of respite care, a very small amount of respite care for them, not being told about possible benefits that are available to them, having to find out by talking to each other, and it is only when people begin to set up little support groups that they get somewhere.

Sir Hugh Taylor: Absolutely, yes.

Q100 Geraldine Smith: Also, the co-ordination between social services and health which is very, very bad. Quite often it is passing the buck from one to the other so nobody accepts responsibility and they will say, "This is health, you need to contact health" and they will say, "Oh, no, it is social services" and the poor parents are caught right in-between and are having to cope with difficulties in their own lives because of the child's behaviour as a result of their autism. What assurances can you give me that it is going to work better on the ground and will be joined-up especially between health and social services? I guess what you really have to do is make a good case to the Treasury for additional resources.

Sir Hugh Taylor: This is really about a process of engagement. It is important to recognise that the voices of people with autism and their carers and families are being heard.

Q101 Geraldine Smith: How are you going to engage on the ground in Morecambe and Lancaster? What can I go back and tell those parents? How are you going to engage with them and how is it going to be improved?

Sir Hugh Taylor: What we would like them to do, first of all, is to feed back into the consultation which we have just launched on our strategy. There will be a lot of different ways in which they can do that which are set out in the strategy. We want to hear their voices repeating back, if you like, those key messages and in particular giving practical examples of their own experiences and how they could be helped. Alongside that we will be talking to people in PCTs, local authorities and third sector organisations to try and get exactly what it says in the Report: better strategy and assessment, better awareness and, frankly, better services because until we get people out there doing something about it nothing will happen. I would love to be able to sit here in front of this Committee and say I have got a magic wand to wave over this but I have not. What I have got is leadership responsibility with my Department for following this through. We have got a commitment to publish a strategy and a Bill, a commitment to follow that up with statutory guidance which will be binding on local authorities and NHS bodies covering many of the issues set out in this Report and in the consultation document that we have got. There is a real sense of momentum behind this. What is really imperative though is that barking out orders from the top is not going to be the way to do it, we have got to lead the process of engagement with the field.

Q102 Geraldine Smith: Do you think you have got enough specialists to make the diagnosis?

Sir Hugh Taylor: No, we need to build up capacity and capability potentially in a number of areas. I know from the limited amount of listening I have done to people with autistic spectrum conditions, the sense that they feel they are being pushed from pillar to post on diagnosis is a very real one. I am sure that is one of the areas we have got to follow through.

Q103 Geraldine Smith: I guess often it is not clear-cut if there are other disabilities combined with autism.

Sir Hugh Taylor: No. They may have other disabilities. They may have associated mental health conditions and sometimes I know that can present a confusing picture to professionals as well as to them as individuals, so this is not completely straightforward.

Q104 Geraldine Smith: Can I ask the DWP, you said before that you were making progress but if that survey is right and there is only 15% of people with autism in full-time employment then that seems pretty poor to me and you obviously need to make a lot more progress. I am not clear about how they got the information for the survey because how do you find out how many people are actually working and managing with autism in the workplace?

Ms Sudworth: Absolutely, we do need to make more progress on the employment rates in a range of groups. For our labour market information we use the Labour Force Survey. When you start to try and look at particular disabilities within that you get down to quite small sample sizes, so it is difficult to get an accurate picture of what the employment rates are for some of these particular disability groups. What tends to happen is that there are other sources of information like the survey information that presumably has been used to get this particular rate. One of the areas in the Labour Force Survey that does cover some people with autism is the category of learning disability and difficulty and that illustrates one of the problems we have because that gives you an employment rate of around 15% but the margin of error is as much as 4 percentage points each side of that, so it is genuinely quite difficult sometimes to make an accurate estimate of the employment rate of particular groups but we can all accept that the employment rate of people with autism is low and we need to do something about that.

Q105 Geraldine Smith: Do you think as well we should be maybe promoting some of the positive qualities to employers? A love of routine and rules seems ideal for a lot of employers and if there are certain jobs where you are working on your own and doing routine tasks I can see employers could actively seek someone with autism to be employed in that way.

Ms Sudworth: I think that is right. We do a lot of work with employers, both through the Employers Forum on Disability but also directly, to promote the benefits of employing people with a range of disabilities. In fact, in our Employ ability campaign that has been running over the past year the online materials feature a case study of somebody with Asperger Syndrome and talks about the positive contribution that person has made to their employer. I believe they are a computer programmer. Absolutely, it is important to make the case that disabled people can be very effective employees.

15 June 2009 Sir Hugh Taylor KCB, Mr David Behan CBE, Mr Hardip Begol and Ms Rebecca Sudworth

Q106 Geraldine Smith: Finally, can I just make a point on supported housing and how important it is to have that within localities rather than people having to go long distances from their families. That really is something you need to concentrate on.

Sir Hugh Taylor: Point taken.

Mr Bacon: The key to this surely is employment. There is not a silver bullet or magic wand but, insofar as there is anything approaching one, it has to be around employment because that addresses the huge chunk of people who are not working who could, it addresses partly the money problem and the mental health issues. I have a certain sense that you are all engaged in this and, Ms Sudworth, you have done your Department proud in that when you get back they are not going to say, "God, why did you say that?" In terms of not dropping your Department in it I think you have done an excellent job, but I fear you have been slightly outgunned by Sir Hugh. Although, of course, this is a health issue and, therefore, the Permanent Secretary for Health is here, it is also fundamentally, if we are going to solve this, an employment issue. I did not feel content with the answers that I got from you which were basically to try to get answers to these questions, and I will put them in a very clear way and please do not necessarily answer them now but if you could look at the transcript and then answer.¹ How many Jobcentres are there and, presumably, how many Jobcentre managers? How many staff are there in Jobcentres? How many of those staff have some background knowledge of autism and, therefore, by extension, how many do not? By when will those who do not, get to the point where they do? That is really what I am trying to get at. Presumably there are team meetings and it would be possible for this to be brought up with material which I am sure the National Autism Society would be happy to provide, and you could have a training module that lasted 20 minutes, which would not preclude more detailed training or specialists, but I bet if the will were there to do it—and I am sure Sir Leigh would be nodding at this if he were sitting where you are—quite a lot could be done to make sure that every employee of a Jobcentre knows something about this within three months.

Chairman: I think you would say "yes" to that.

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Q107 Mr Bacon: I did not hear "yes".

Ms Sudworth: Yes.

Angela Browning: People on the spectrum will do a whole range of work and we know that they make very good employees. I just wanted to share with the Committee that in preparation for the Autism Bill we had a meeting here with people trying to get into work and one young man came along—this was just a couple of months ago—with his parents and he had got a university degree. The first year of university had not worked out because he could not cope with living away from home so they changed his university and he completed his degree living at home with mum and dad as usual, but he could not get a job. Here was this young man with a degree here in this House, with mum and dad doing all the talking saying "We have tried this, we have tried that" and the conversation went on, and purely almost as an afterthought Cheryl Gillam, my colleague who is taking the Autism Bill through, said to him, "And what have you got a degree in?" and he said, "I've got a masters in astrophysics". It just encapsulates what autism is about: he had a degree in astrophysics but mum and dad need to help him find a job, and that is autism.

Q108 Chairman: Thank you very much for what has been a very good and groundbreaking hearing for this Committee. I am sure that, once again, we have done very useful work. It has been a very interesting hearing for me because my uncle was autistic. He was born during the First World War and he had a brilliant mind. You could give him a date 20 years before and he would tell you what day of the week it was, but for all his life he never had a job and lived with his mother. It is so sad that these people are just forgotten by society, so we are relying on you, Sir Hugh, to change things.

Sir Hugh Taylor: Thank you very much. If I may say so, I think this Report is a very good platform for taking that forward and obviously we will take into account any further recommendations which the PAC makes. On a personal note, may I say this is the first time in my life, and I have felt slightly uncomfortable, that I have been addressed as "Sir Hugh" and if after the weekend there is any question of my getting too big for my boots, there is nothing like a PAC hearing to bring me down to earth!

Chairman: Thank you very much.

Supplementary evidence submitted by the Department for Work and Pensions

Q106 *How many Jobcentres are there, how many managers and staff, and how many staff have some background knowledge of autism?*

There are frequent staff changes in Jobcentre Plus which means that they have a continuous need to ensure all their staff are aware of how to work with a wide range of customers. Therefore, a one-off awareness session in each office would have limited benefit.

In February 2009, Jobcentre Plus had 741 Jobcentre Plus offices open to the public, with about 572 Full Time Equivalent (FTE) Jobcentre Office Managers, around 917 Adviser Services Managers and approximately 29,847 FTE staff in total. A number of these will be people working in non customer facing roles.

Jobcentre Plus staff deal with a wide range of customers presenting many different requirements. Potentially they need to be able to assess the impact on a customer of numerous medical conditions and because of this they do not receive specialist learning on a particular condition. Instead, they receive a comprehensive programme of learning designed to equip them with the full range of knowledge and skills required to support all customers, including those with autism. On completion of their learning route-way staff are able to deal effectively with all the issues that a long term health condition can present.

Our customer facing Jobcentre Plus staff make good use of our foundation e-learning around diversity and equality, including The Diversity and Equality Awareness for Excellent Customer Service. This provides a general awareness of disability, disability issues and the responsibilities of JCP both as an organisation and individuals. It also provides an understanding of the “specialist” roles of Disability Employment Adviser, Incapacity Benefit Personal Adviser, Work Psychologist and Access to Work Adviser, leading to a more seamless service for our customers with disabilities, including autism.

Customers are supported by advisers who receive more in depth training about disability issues. Around a third of Jobcentre staff are advisers, all of whom follow a training route way, which includes the mandatory Adviser Skills—Helping Customers Move “Towards Sustained Employment” event, this training includes a broad understanding of how to work with customers who are autistic.

The event is underpinned by a number of health and personal circumstance information stencils known as SKIPPs (Specialist Knowledge, Interview Planning, and Preparation stencil). The Autism Spectrum Condition SKIPP was developed in consultation with Work Psychologists and reviewed by the National Autistic Society and forms part of the recommended adviser training programme.

The SKIPP provides advisers with an awareness of the condition, the effects that it might have on individuals ability to find and retain employment and the possible types of support an individual might need in employment. In May, we highlighted the link to the SKIPPs information on various staff web pages, also reminding staff that Access to Work can help support customers with autism.

The Jobcentre Plus Learning Division will review all the SKIPPS with the involvement of the appropriate lobby groups by October 2009. At the same time, we will be looking for ways to advertise the SKIPPS more widely and promote their use, particularly ensuring ease of access on the Jobcentre Plus intranet site. The Learning Division is in the process of reviewing other learning products, identifying gaps to support the demanding changes to the adviser role in the current climate.

Along with the review of the SKIPPS we have been exploring ways of improving and continuing to develop skills and knowledge in the most valuable, cost effective way. In order to support advisers and others who wished to develop an even greater understanding of autism and the issues related to employment, Jobcentre Plus publicized the Employers Forum on Disability’s (EFD) telephone tutorial on reasonable adjustments for autism.

The tutorial took place in April and though a significant proportion of the total number of delegates were Disability Employment Advisers, other staff also took advantage of this learning opportunity and actively questioned Noel Hastings of NAS during the Question and Answer session.

A senior Jobcentre Plus official is due to meet with Mark Lever of NAS on behalf of our A/CEO on 6 July and we will be happy to discuss our plans to improve awareness for staff at that time and explore what else could be done. We will also explore with NAS what additional information about autism can be placed on our intranet. All jobcentre Staff have access to our intranet. It is a key communication tool.

25 June 2009