

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

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Foreword

All adults with autism¹ deserve to get the support and services they need to fulfil their potential. I know that far too often adults with autism are let down, and are unable to access the kind of support that would make a real difference to their lives and the lives of their families. This is not acceptable.

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

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

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

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

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

Mark Lever

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

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

Introduction

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

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

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

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

General principles

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

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

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

1. Health

This chapter looks at multidisciplinary assessments and diagnosis, as well as post-diagnostic support, mental health, general health and accessible healthcare for people with an ASD.

Vision: Adults with an autism spectrum disorder (ASD) are able to access a needs- and skills-based assessment (including diagnosis) from suitably-qualified professionals from a multi-agency team. All adults with an ASD get the health services and support they need at the place and time they choose.

This means that:

- multidisciplinary/multi-agency assessments and diagnoses of ASD are available in every local area
- post-diagnostic support is always available to support the individual and the family concerned
- services are well-integrated so that diagnosis is not isolated from the support and services available and the comprehensive assessment of need made as part of the diagnosis contributes to the development of an ongoing personalised package of care. The importance of continuity of care is recognised and understood.
- all health and mental health professionals have appropriate training in ASD
- a range of preventative interventions are provided locally to promote wellness, increase levels of social inclusion, and reduce the risk of people with ASD developing mental health conditions
- healthcare services are fully accessible to people with ASD and all healthcare professionals have an understanding of the condition, meaning that people with ASD are given the healthcare and the support they need to live healthy lives and the risk of diagnostic overshadowing is eliminated.

What things are like now

Diagnosis and post-diagnostic support: People with an ASD find it hard to access the support they need. Without a diagnosis, it is even more difficult for them and, in particular, for those with Asperger syndrome or high-functioning autism, to access support. However, a lack of diagnostic services means that the vast majority of adults with ASD remain undiagnosed, and are unlikely to be able to access the services they need. Where diagnosis is available, post-diagnostic support is poor. The key challenges are:

- most GPs do not have sufficient knowledge to screen people for ASD, nor do they have access to local expertise for referral
- local secondary mental health providers generally will not undertake an assessment of people with ASD unless there is significant psychiatric co-

- morbidity, and only a fraction of Primary Care Trusts (PCTs) have a specialist diagnostic service for adults with ASD
- due to a lack of capacity, when a diagnosis is available, it is unlikely to be accompanied by appropriate levels of post-diagnostic support and counselling for the individual and their families
 - as there is no formal care pathway for adults with ASD, diagnosis happens in isolation, and there is no mechanism to facilitate the subsequent development of a personalised package of care.

Health care service inequalities: A lack of understanding of ASD among healthcare professionals means that additional health problems are not always recognised. Moreover, if adjustments are not made for a person with an ASD, the experience of visiting a health setting can be distressing. The key challenges are:

- reasonable adjustments for people with ASD are generally not made (e.g. longer appointment times, timely and simple appointment booking procedures)
- there is a lack of understanding among healthcare professionals of co-occurring conditions experienced by many people with ASD (e.g. dyspraxia, ADHD) and of the sensory issues experienced by many people with ASD
- the needs of adults with an ASD cuts across traditional health care service boundaries. As a result, adults with ASD are frequently excluded from services as they 'fall through the gap' between services. This is particularly true for those with Asperger syndrome or high-functioning autism who do not meet the criteria for a learning disability service, despite the lack of a legal basis for these criteria.

Mental health: Adult mental health professionals generally lack training, expertise and experience in ASD diagnosis, assessment and support. As a result:

- misdiagnosis or inappropriate treatment (i.e. medication or therapy) is regularly reported
- there is a lack of preventative measures and support in place to reduce the risk of adults with ASD experiencing deteriorating mental health
- there is a lack of co-ordinated regional specialist adult ASD services to be able to assess and manage the most complex case (including forensic services).

Key recommendations

1. Local leadership, local hub and regional team

1.1 An ASD "hub" should be set up in every local area. It will be jointly funded by local authorities and PCTs. Its responsibilities will include:

- skills/needs-based multidisciplinary assessments

- diagnosis and post-diagnostic support, ensuring that an appropriate diagnostic service is available to adults with an ASD in every local area
- provision of support and advice to all public bodies in the local area which will come into contact with people with an ASD
- signposting to and liaison with mainstream services
- support for individuals to navigate services and signposting of overlapping services
- training
- ensuring appropriate support and services for people with ASD are developed locally
- involving people with ASD, their families and user-led organisations and other relevant third sector organisations in service development.

1.2 Before these hubs are set up, local authorities and PCTs should ensure that the responsibilities outlined above are taken on by another part of their respective organisations.

More details on the hub, its responsibilities and composition are outlined in appendix 1.

1.3 Each Strategic Health Authority (SHA) should establish a regional ASD team, funded through specialist commissioning arrangements. It should have responsibility for the following areas.

- A) Commissioning support for the small group of people with an ASD who have the most complex needs and/or forensic needs, including those who present severe challenging behaviour, those who pose a serious risk to themselves and others and those who have complex or treatment-resistant co-morbid psychiatric disorders. This will include:
- providing diagnosis/treatment advice to local services, so that individuals who fall into this category can be seen, as far as possible, in their local communities
 - case-managing those individuals who will still need to be placed out of the area.
- B) Supporting the local provision of services and the local hubs by:
- providing advice, supervision, consultation and training
 - auditing and evaluation of local services
 - monitoring need in order to support commissioning.

2. Data collection and strategic planning

2.1 PCTs and local authorities must ensure that a multi-agency and anonymous database of adults with ASD is developed and used regularly to assist with commissioning and future service planning.

2.2 PCTs and local authorities should set up protocols to ensure effective transfer of data on individuals as they move between services.

2.3 PCTs and local authorities must ensure that Joint Strategic Needs Assessments (JSNAs) specifically and comprehensively include all the needs of adults with ASD. This will include recognising sensory, communication, access and social needs.

2.4 PCT and NHS trusts must ensure that their disability equality schemes include specific action to address the health needs and health inequalities facing people with ASD. All NHS Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, reasonably adjusted health services to support the needs of patients with ASD (this might include taking into account sensory issues, allowing someone to accompany a person with ASD in all healthcare settings, and ensuring that clear information is given to the individual about procedures).

2.5 All NHS Trust Boards must ensure that the views and interests of people with ASD and their carers are included in the planning and development of services, pursuant to their duties under section 242 NHS Act 2006.

2.6 PCTs and local authorities must have clear protocols to explain the split between community care and NHS continuing care to people with an ASD and their families.

2.7 The regional Government Offices and SHAs should work together and with the regional team to develop regional commissioning plans for diagnosis, appropriate supports and specialist services, including forensic services. They should also develop a process for sharing good practice among local services. The model of regional consortiums could assist in this.

2.8 The Department of Health must work with SHAs to support PCTs in commissioning services for people with ASD and in developing appropriate care pathways for people with ASD.

2.9 The Department of Health must produce guidance for Local Authorities and PCTs on commissioning services for people with ASD in line with world class commissioning.

3. *Diagnosis and post-diagnostic support*

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

3.2 Local Authorities and PCTs should support family carers following a diagnosis and offer them relevant information and training on how to support their relative.

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

3.5 Third sector organisations should further develop and advertise the support and training they offer for families, including siblings, spouses and partners and parents of adults with an ASD.

4. Accessible healthcare

4.1 GPs should identify all people with ASD in their practice and proactively invite them for annual health checks (which include prescription reviews) and make reasonable adjustments when meeting with people with ASD (e.g. longer appointment times).

4.2 PCTs should set up a programme for recording access and communication needs on patient records, where requested, so that an individual's needs can be easily identified and met when they are moving between services.

4.3 The Department of Health should produce best practice guidance for healthcare settings, demonstrating the range of adjustments that could be made to support patients with ASD. This support might include allowing someone known to the person to accompany them to act as an "ASD translator", making reasonable environmental and sensory adjustments, and ensuring that the individual is given understandable and accessible information about procedures.

5. Training

5.1 PCTs must ensure that NHS continuing care assessments of a person with an ASD are carried out by a professional with suitable ASD training and expertise. Where training has not yet been completed, staff carrying out assessments should seek assistance from local partners (such as third-sector organisations) with expertise in ASD to assist them.

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

5.3 The Department of Health must work with those who have responsibility for the provision and regulation of undergraduate and postgraduate clinical training to ensure that the curriculum includes mandatory training in ASD. Training should be competence-based and involve people with ASD in its design and provision.

5.4 The Department of Health should work with professional regulatory bodies and education bodies to ensure awareness of the needs of people with ASD are incorporated into training for all healthcare professionals.

6. Evaluation and accountability

6.1 The Department of Health should work with the Care Quality Commission to develop standards of care for people with ASD for use in the inspection process.

7. Research

7.1 The Department of Health should support a research and development programme that informs current and future service provision. Research and Development priorities include:

- evaluation of current levels of service provision for services at local and regional level and mapping against predicted current and future need
- investigation of the costs and benefits of specialist diagnostic and support services for individuals with complex ASD
- investigation of the impact of ASDs on adolescence and adulthood
- investigation of so called “inappropriate medication” for people with an ASD and measures that can be developed to prevent this
- evaluation of biomedical interventions such as the impact of metabolic and digestive problems and ASD
- the differing impact of ASD, depending on gender.

2. Social Inclusion

This section deals with accessing the appropriate support, including social support and community care, that people with ASD need in order to play as full a role as possible as citizens and be included in society. It also looks at inclusive living and housing, ensuring access to meaningful activities as well as making the physical and sensory environment accessible to people with ASD. Employment – a key aspect of social inclusion - is discussed in the employment chapter.

Vision: All adults with an autism spectrum disorder (ASD) are treated as equal citizens and are fully and appropriately supported to fulfil their potential and participate in society as much as they are able.

This means:

- having appropriate and timely support that both promotes social inclusion for people with an ASD and prevents their social exclusion
- having a range of support available that reflects the depth and complexity of ASD
- having choice over living arrangements – both where and with whom
- accessing meaningful activities during the day and during the evening, including employment or voluntary work and non-work-related or leisure activities that are important to the individual, established and reviewed through an ongoing person-centred approach
- accessing both universal services and ASD-specific services, as appropriate
- being able to access support regardless of age, co-morbidities, co-existing conditions, gender, race, cultural issues, nationality, sexuality and religion
- ensuring that the physical, sensory, environmental and health needs of people with ASD are taken into account as they access support and the wider community (including accessing transport).

What things are like now

Appropriate support and access to meaningful activities: Approximately two-thirds of adults with ASD are unable to access the support they need and the provision of services for people with ASD at a local level is patchy and inconsistent. Barriers to accessing appropriate support include the following.

- *Current structure of social services and local leadership:* Social services departments are generally divided into teams, and people with ASD can come into contact with either learning disability teams or mental health teams. However, many people with ASD, and particularly those with Asperger Syndrome or high-functioning autism, frequently “fall through the gap” between learning disability teams and mental health services, as both refuse to take responsibility for them. This is because ASD is neither a learning disability nor a mental health problem. Barriers to access are

compounded by a lack of local leadership on the provision of support to people with ASD.

- *Eligibility criteria:* Despite the lack of any legal basis for doing so, some local authorities continue to state that certain groups of people with an ASD, for instance, people with Asperger syndrome, are not eligible for community care services. Evidence from the CSCI review of eligibility criteria shows that people with ASD are particularly excluded under the current system, created by the *Fair Access to Care Services* guidance.
- *Strategic planning:* Few local authorities know how many people there are with ASD in their area. As a result, they do not plan for or commission services that are meaningful for the individual and would help promote wellness and social inclusion (e.g. social skills and life skills training).

Inclusive/independent living, housing, transport and accessibility:

People with ASD are not always able to access the range of options and support available when choosing to live independently, when looking for housing and participating in their wider preferred community. Large numbers of people with ASD are dependent on their families and continue to live in the family home. Key barriers preventing people with ASD from living independently include the following.

- *Strategic planning:* There are few local records of the number of adults requiring housing and support services and housing strategies rarely include the needs of people with ASD.
- *Housing support:* Much-needed support to live independently (e.g help with managing bills) is not always available to people with ASD.
- *Housing design:* Design of housing is often inappropriate for people with ASD. This can be detrimental to their health and well-being (e.g. poor sound insulation may cause stress to those with sensory sensitivities).
- *Transport:* Transport is often inaccessible for people with ASD and more support is needed for people with ASD to access transport (e.g. transport training).
- *Accessing the community and living independently:* Independent living skills training is not widely available. Public buildings and spaces can also be inaccessible for people with ASD, largely due to sensory issues.

Key recommendations

1) Local leadership and Local Hub

1.1 Local Authorities must implement the Director of Adult Social Services' guidance and appoint a named individual with responsibility for ASD.

1.2 This named individual will have responsibility on behalf of the local authority to set up an ASD team or "hub" in their local area. This hub should be jointly funded, staffed and resourced by local PCTs and Social Services Departments. The hub would sit in either the PCT or in social services, depending on where there is the

most expertise, or within the Care Trust where one has been established. It will be overseen by a panel that includes people with ASD, parents and carers as well as professionals.

- The hub would be expected to support people with ASD to navigate health and social care services, where this support is not available elsewhere, and act as a link to overlapping services.
- The hub would be expected to offer support and advice to all public bodies within a local area that are providing support to people with ASD. This would include offering support to learning disability services and mental health services that are supporting people with an ASD.
- The hub would provide support, advice and training to others in the local area (e.g. employers).

1.3 Before these hubs are set up, local authorities and PCTs should ensure that the responsibilities outlined above are taken on by another part of their respective organisations.

1.4 The Department of Health should work through its government offices to identify the support needed locally to improve local services. The Department of Health should provide sufficient funding to each local authority and PCT to improve local capacity and establish and maintain effective services and support, which will include funding for the hub.

1.5 The Department of Health must support local authorities and PCTs to set up local hubs, by developing guidance outlining the composition of the team and its role.

More details on a model for the hub are outlined in appendix 1.

2. Data collection and strategic planning

2.1 Supported by central government, local authorities and PCTs must develop measures to identify and keep a record of adults with ASD in their catchment area. This should be informed by information from children's services and other relevant agencies. Local authorities and PCTs should ensure that protocols are in place for sharing information between child and adult services, as well as other relevant agencies, to support this, while respecting data protection principles.

2.2 Local authorities should learn from screening programmes undertaken in learning disability services in Greater Manchester to see how many people in the services also had ASD and whether the service was appropriate for their needs. This screening should also look at co-morbid/co-existing conditions.

2.3 PCTs and local authorities must ensure that Joint Strategic Needs Assessments (JSNAs) specifically and comprehensively include all the needs of

adults with ASD. This will include recognising sensory, communication, access and social needs.

2.4 PCTs and local authorities should ensure that information in JSNAs relating to people with ASD, as well as the views of relevant voluntary user-led organisations, other relevant third-sector organisations and the views of local people with ASD and their families, are used to inform Local Area Agreements (LAAs).

2.5 When producing disability equality schemes, public bodies such as PCTs and local authorities should ensure that they include a focus on ASD and involve people with ASD and their families in their production.

2.6 Local authorities should ensure that they are involving user-led organisations and local people with ASD and their families when developing ASD services and other relevant services. This could mean setting up an equivalent of the Learning Disability Partnership Board for ASD.

2.7 Local authorities and PCTs should keep a database of local ASD service providers and use these databases to involve them in service development plans.

2.8 Government offices and Strategic Health Authorities should develop a programme for sharing best practice among local authorities and PCTs. This may include setting up regional consortiums, such as the Greater Manchester Consortium, which supports expertise-sharing and joint commissioning arrangements, as appropriate. Regional ASD teams could help co-ordinate these consortiums.

2.9 Working with best practice local authorities and through trialling local schemes, the Department of Health should develop models to support local authorities to introduce local record keeping of people with an ASD.

3. Community care and support

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

3.2 Local authorities should review the operation of their local Fair Access to Care Services policy in the light of the CSCI findings to ensure that it is not discriminating against adults with ASD.

3.3 Every adult with ASD must be able to access a person-centred plan to support that adult to achieve his or her goals. Local authorities should ensure that those

who are not eligible for community care support under FACS are able to access support to develop a person-centred plan.

3.4 All local authorities and PCTs should individually carry out a review of their out-of-area placements, assessing their suitability for adults with an ASD.

3.5 Local authorities should review current provision of meaningful activities for adults with ASD that promote independence skills and work to develop their independent living skills.

3.6 Local authorities and PCTs must invest locally in specific services that help tackle social exclusion among people with ASD from across the spectrum. This will include social skills training, social groups, job preparation schemes and befriending. It will also include other specific supportive programmes (e.g. transport training, awareness and training programmes on how to access housing/employment/social care/ healthcare). It may also include assigning a family support worker or a lead professional to every individual with ASD in a local area. Such services should be available to all people with ASD regardless of whether they are eligible for support through FACS.

3.7 The Department of Health should support local authorities and PCTs in the development of new services for adults with ASD, such as social skills training, by developing best practice guidance outlining how to set up these services. User-led organisations, provider organisations, people with ASD and their families should be involved in developing this toolkit. The Cabinet Office's work on the Adults Facing Chronic Exclusion (ACE) pilots should be used to inform what support services are most effective in tackling social exclusion.

3.8 The Department of Health must conduct a review into the adequacy of the level of funding allocated to individuals with ASD through direct payments and individual/personal budgets and issue guidance to local authorities on appropriate levels of funding to be made available.

3.9 The Department of Health must review the Fair Access to Care Services statutory guidance to ensure that guidance on its application outlines how community care assessors should ensure that the needs of people with ASD are properly assessed and met.

3.10 The Department of Health should develop a model for analysing the costs and benefits of investing in low-cost, high-impact supports to tackle exclusion to demonstrate potential long-term cost savings for PCTs and local authorities.

4. Housing

4.1 Local authorities should ensure that their housing strategy includes the range of needs of adults with ASD (including environmental and sensory needs), looks at the adaptations that may be needed for an adult with ASD and ensures that people

with ASD can have a real choice over where they live. It should also include provision for people with ASD who become homeless. Local authorities should involve people with an ASD in developing their strategies.

4.2 Local authorities should review the support offered by their Supporting People services with a view to ensuring that appropriate housing support is available for adults with ASD.

4.3 Local authorities should ensure that advocacy and other support is available for individuals with ASD to help them find and secure their preferred accommodation and to manage budgeting.

4.4 Government offices should support local authorities to ensure that local housing strategies include the needs of adults with ASD across the spectrum, recognising sensory, communication, access and social needs.

4.5 The Department of Health's work with the Department of Communities and Local Government on how mainstream housing policies can best be made inclusive to people with learning disabilities should be expanded to include people with ASD, regardless of whether they have an accompanying learning disability.

4.6 The Department of Health should work with the Department of Communities and Local Government on developing guidance on the accessibility requirements of housing for adults with ASD.

5. Transport

5.1 Local transport authorities should ensure that local transport plans include people with ASD and that people with ASD are properly involved in the development of every plan.

5.2 Local authorities should ensure that transport training is available for adults with ASD in their area. This could be delivered through the hubs, by extending any current provision (e.g. through the Learning Disability team) or with support from local third-sector organisations.

5.3 Government offices should support local authorities to ensure that local transport strategies include the needs of adults with ASD across the spectrum, recognising sensory, communication, access and social needs.

5.4 The Department of Health should work with the Department for Transport to produce guidance on making public transport accessible for people with ASD.

5.6 The Department for Transport should amend the eligibility criteria for receiving a blue badge so that it reflects the specific difficulties experienced by people with ASD.

6. Physical and sensory environment

6.1 The Department of Communities and Local Government should review Part M of the building regulations to make buildings accessible for adults with ASD.

6.2 The Department of Communities and Local Government should work with relevant bodies such as CABE to develop awareness-raising for corporations and employing bodies on how to improve the environment for people with ASD (lighting/noise etc).

7. Evaluation and accountability

7.1 The Department of Health should work with the Care Quality Commission (CQC) on developing standards for inspecting the services provided for people with ASD and ensuring that their current inspection regime captures specifically the experiences of people with ASD.

7.2 The Department of Health should work with Communities and Local Government and the Cabinet Office on developing national indicators on outcomes for adults with ASD in a local area.

3. Choice and Control

This section covers person-centred planning, advocacy, transition planning and involvement in service development.

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

This will mean that:

- all adults with ASD have access to the support they need to develop and continue to revise personal goals and objectives and develop an ongoing person-centred plan that can help them to meet the goals used to determine their support
- all adults with ASD have the support they need to communicate in the way they choose
- adults with ASD, their families and supporters and user-led organisations play a central role in relevant policy development (national and local) and in local service development.
- user-led organisations are referred to in preference to non-user led organisations
- all adults with ASD can access an advocate who has training in ASD if they need one
- transition planning begins at 14 for all people with ASD and people with ASD and their families are fully involved in this process, so that the plan supports the aspirations of the young person with ASD.
- child and adult services work together to ensure a smooth link between services
- the autism rights movement is acknowledged at national level
- people with ASD are able to receive personal/individual budgets and take these as a Direct Payment if they want and feel able to use it with the right support. Assessments for personal/individual budgets are able to accurately and fairly take into account the range of needs of people with ASD and personal/individual budgets are sufficiently-funded to meet the needs of individuals with ASD.

What things are like now

Personalisation: Individuals with ASD are less likely than other people with disabilities to have support plans that are holistic and meet their unique needs. Only 27% of adults with ASD currently have a person-centred plan or care plan. Moreover, people with ASD currently lack choice and support when choosing to live independently, when looking for employment, when accessing higher education and when participating in their wider community. Involvement in policy

making and service planning of people with ASD is not standard practice and can be tokenistic.

Transition Planning: There is a high level of dissatisfaction with the process of transition to adult services. If transition fails, adults often find themselves embedded more firmly in the family home, which can result in them leading isolated lives and an increase in family stress. The key challenges to effective transition are:

- *information sharing:* information is not always shared between child and adult services, which can impair a smooth transition process
- *failure to begin transition early enough:* transition plans are often outlined at the 'last-minute', leaving little time for people with ASD and their families to consider their options and resulting in them being matched to services based on availability rather than need, while making the transition process more stressful.

Advocacy and self advocacy: Advocates are not widely available and generally do not have a good understanding of ASD. There is also a lack of skills training in self-advocacy.

Key recommendations

1. Personalisation

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

1.2 Local authorities and their partners should develop robust measures for ensuring that person-centred plans are ongoing, regularly revisited, holistic and developed in a transparent way.

1.3 All local authorities must ensure that their Resource Allocation Systems (RAS) for personal/individual budgets make accurate and fairly account of the needs of adults with ASD.

1.4 All local authorities must consult with people with ASD and their families when developing their RAS and should pilot any new system with people with ASD.

1.5 Local authorities should ensure that brokerage and advice services on the use of individual/personal budgets are available. This will include support and advice on budgeting. The need for brokerage should be taken into account when allocating resources to an individual/ personal budget.

1.6 Training for personal assistants employed through an individual/personal budget should be funded by the local authority.

1.7 Local authorities, PCTs and their partners should develop measures to support people with ASD to access universal services and should use community resources to help support people to live within their preferred community, whether or not they are eligible for social care funding. This will include the development of low intensity supports, such as social skills groups for all adults with ASD.

1.8 Local authorities should develop capacity locally on the use of alternative communication methods including Augmentative and Alternative Communication (AAC) as well as developing training in their use for individuals with ASD and their families.

1.9 PCTs and local authority commissioners should consult with local people with ASD and their families to assess the local need for extra capacity in speech and language therapy services for adults with ASD.

1.10 Local authorities and PCTs should ensure that all their publications are produced in accessible formats for people with ASD.

1.11 Local Authorities, PCTs and their partner organisations should ensure that appropriate information is available for people with ASD to make informed choices about what they want to include in their person-centred plan and what services they can access to support them in meeting their aims.

1.12 Local authorities should conduct an audit of the people in their local area who use non-verbal communication and use this to inform service planning and production of communications in accessible formats.

1.13 The Department of Health must commission further research into the impact of individual budgets on people with ASD to look at how they can be best implemented for this group of people. This research should be informed by the work already completed by the IBSEN team.

1.14 Following this research, and in partnership with relevant third-sector organisations, the Department of Health should produce a toolkit to support local authorities to make individual/personal budgets work for people with ASD.

1.15 When piloting health budgets, the Department of Health should ensure that people with ASD are properly included in the pilot scheme and the evaluation.

1.16 The Department of Health should work with the Care Quality Commission to ensure that the inspection process reflects the importance of person-centred care for people with ASD.

1.17 The Department of Health will work with the Care Quality Commission to ensure that the inspection process reflects whether the needs of people with ASD are being met through individual/personal budgets.

1.18 The Department of Health, local authorities and PCTs should ensure that training programmes on ASD highlight the importance of communication needs for people with ASD. This should include raising awareness of Augmentative and Alternative Communication (AAC).

1.19 The Office for Disability Issues (ODI) should work across Government to ensure that Government publications are made available in accessible formats for people with ASD. This will involve developing a toolkit for other Government departments and for other public bodies. People with ASD should be involved in the development of this work.

1.20 Provider organisations should ensure that all people with ASD they support have a person-centred plan and that these plans drive the type and style of support provided. Provider organisations should also review and improve the support provided and ensure that agreed outcomes continue to be met.

2. Relationships

2.1 Government offices, through regional ASD teams where appropriate, should work with local service commissioners and providers to develop systems and processes, which will enable people with ASD to build and sustain personal relationships.

2.2 The Department of Health should produce toolkits for health and social care professionals about promoting safe personal relationships within the laws of safeguarding and human rights.

2.3 The Department of Health must ensure that the specific needs of people with ASD are taken into account in the reform of “No Secrets” and any legislation that is developed on safeguarding.

2.4 The Department of Health should work with the Care Quality Commission to address the role of registered care services in supporting people to develop and sustain relationships, including sexual relationships, increasing access to mainstream leisure and recreational services, and supporting people to keep in contact with their friends and families.

2.5 The Department of Health should develop best practice guidance for statutory bodies on working with parents with ASD.

3. Involvement in service development

3.1 Local authorities and PCTs must involve relevant ASD user-led organisations, other third-sector organisations, people with ASD and their families in local decision-making and in the development of new relevant services, in line with commitments under the Disability Equality Duty.

3.2 Local authorities and PCTs should ensure that local consultations are accessible to people with ASD by publishing accessible materials and allowing people to respond in a way most appropriate to them.

3.3 Local authorities will ensure that a user-led organisation in their area modelled on existing centres for independent living, required by 2010 through a central target, can provide support for people with ASD and their families.

3.4 Local authorities should support local involvement networks (LINKs) to include people with ASD in their work.

3.5 Third-sector and provider organisations should increase the involvement of people with ASD in their work and, in particular, should look at increasing the numbers of people with ASD involved in their management structure.

3.6 The Department of Health should establish national forums for the involvement of people with ASD in the development of national policy that will impact on them.

4. Transition

4.1 Local authorities and their partners must comply with their statutory duties to ensure a proper transition to adulthood for young people with ASD, including those under the SEN Code of Practice and the regulations and guidance for care leavers.

4.2 Transition planning should identify future need in all areas, including employment, education, social care, health and housing.

4.3 Transition plans should also be made available for all young people who have a special education need as a result of having ASD, but who do not have a statement of special educational needs.

4.4 Local authorities and PCTs should ensure that a person-centred plan, reflecting the aspirations of and developed in partnership with the young person, lies at the core of a transition plan. The individual, their family/carers/supporters, together with representatives from all relevant local stakeholders, should all be involved in the plan.

4.5 Local authorities must ensure that the Director of Children's Services maintains a multi-agency database of the number of children with ASD in the local area, and that the Director of Adult Social Services regularly reviews this database to assist with transition planning and service development.

4.6 Local further and higher education providers should work with local ASD support services to support the transition process for young people with ASD.

4.7 Local authorities should ensure that Connexions staff are trained in ASD so that they can support transition from education to further education, training or employment.

4.8 PCTs should develop specific protocols for the transfer of clinical mental health care for those young people with ASD in Child and Adolescent Mental Health Services (CAMHS). Where those individuals do not fulfil referral criteria for an adult mental health team, measures should be put in place to support that individual elsewhere. Commissioners must be informed of gaps in services in these instances.

4.10 Local authorities should monitor Connexions databases to ensure that people with ASD are being supported up to the age of 24.

4.11 Transition leads, appointed in every region under Valuing People Now, must ensure that they include the needs of people with ASD, regardless of whether they have an accompanying learning disability.

4.12 Research from the Department of Health and Department for Children, Schools and Families' Transition Support Programme on the transitions to adulthood of young people with ASD must be used to inform any guidance on how best to support young people with ASD through transition.

5. Advocacy and self-advocacy

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

5.2 Local authorities should support the development of local support groups for people with ASD which will offer training on self-advocacy as well as training on peer-to-peer advocacy.

5.3 Government offices, through the regional ASD team where appropriate, should develop an information programme on local advocacy services as well as a programme of best practice sharing on advocacy.

5.4 Government offices, through the regional ASD team where appropriate, should support local authority commissioners to commission high-quality advocacy services which include the provision of advocates with training in ASD.

5.5 Government offices, through the regional ASD team where appropriate, should develop a programme of sharing best practice on self-advocacy training for local support groups.

5.6 The Department of Health should ensure that the national advocacy qualification covers ASD and the communication needs of people with ASD. People with ASD must be involved in its delivery.

5.7 Third-sector and provider organisations should work to ensure that advocates are available for those in their services that would benefit from their support.

5.8 Third-sector organisations should increase capacity around the provision of advocates.

4. Employment

This section discusses employment support, including support to get a job (whether paid or unpaid) and support within the workplace. It covers raising awareness of ASDs among employers and employees. This section also covers financial security for people with an ASD and makes recommendations for improving access to adult education and skills.

Vision: All adults with ASD have the opportunity to work, appropriate to their skills and impairments, and can access the support they need from benefits and tax credits. There are skills and education courses that match the needs of adults with ASD preparing for work. Further and higher education, and lifelong learning, is accessible to adults with ASD.

This means that:

- adults with ASD can access timely and specialist support in preparing for work and looking for work, whether paid or unpaid
- adults with ASD are given the support they need in the workplace
- adults with ASD are not discriminated against during the recruitment process or in the workplace
- employers recognise the valuable skills that people with ASD have to offer
- support and training are given to work colleagues of people with ASD to make sure they understand ASD
- adults with ASD get the support they need from the benefits and tax credits system to ensure their financial security
- adults with ASD are able to access learning opportunities and fulfil their potential.

What things are like now

Work: Only 15% of adults with ASD are in full-time employment, yet a much greater number of people with ASD want to work and could do so if given appropriate and timely support. The following barriers prevent people from getting and keeping a job.

- Very few Government-funded schemes aimed at preparing disabled people for work are ASD-specific, meaning that many people with ASD are unable to access the support they need to find work.
- Access to Work could provide in-work support for people with an ASD but many have difficulty in accessing it. This results in many people with ASD being unable to sustain employment and progress in their careers.
- Department of Work and Pensions (DWP) contracts focus on “payment by results”. This results in little recognition of progression towards work.
- Jobcentre Plus staff (including Disability Employment Advisors) generally have a poor understanding of ASD and are unaware of how to meet the needs of people with ASD.

- There is a lack of support for people with ASD to develop the social skills necessary for finding and keeping a job.

Employers: Awareness among employers of the valuable skills that people with ASD have to offer in the workplace is low. This means that:

- many employers fail to make reasonable adjustments to their workplace
- a lack of understanding of ASD in the workplace leads to bullying and discrimination
- people with ASD are deterred from applying for jobs as advertisements use inaccessible language and often require skills not necessary to the role
- people with ASD are placed at a disadvantage at job interviews due to consistent failure to make reasonable adjustments.

Benefits and tax credits: There is a lack of evidence to show how many people with ASD are accessing the benefits they are eligible for. Anecdotally, people with ASD are not accessing the benefits that they are eligible for. The key reasons for this are:

- many people with ASD are unaware of their entitlement to benefits and tax credits
- those involved in administering benefits (including decision-makers) generally have a poor understanding of ASD
- the criteria for benefits do not always take into account the specific needs of people with ASD.

Education and training: There is a lack of support for adults with ASD in accessing further/higher education or lifelong learning opportunities. E.g. Disability Support Officers and students with ASD are unclear about whether they can use Disabled Students' Allowances to fund social as well as academic support.

Key Recommendations

1. Work

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

1.2 Local Connexions and Jobcentres should build links with local authority or PCT services that support people with ASD to ensure that adults with ASD can access employment support and that knowledge about the individual is shared between services.

1.3 Local authorities should ensure that every individual with ASD has a lead professional responsible for brokering employment support (both pre-employment and once in post).

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

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

1.6 The Office of the Third Sector should improve access to volunteering opportunities for people with ASD.

1.7 The DWP should monitor the number of people with ASD receiving support from employment services (including Pathways to Work, specialist disability employment services and Flexible New Deal) and the number of people with ASD these services are supporting into work. This information should be used to evaluate the success of these schemes and be taken into consideration when awarding contracts for employment support.

1.8 The DWP, through Jobcentre Plus, must introduce mandatory training in ASD for all disability employment advisors.

1.9 The DWP, through Jobcentre Plus, should ensure that all personal advisors receive training in ASD.

1.10 The DWP should develop guidance to Jobcentre Plus Disability Employment Advisors on supporting people who have received a diagnosis of ASD whilst in work.

1.11 The Department for Innovation Universities and Skills (DIUS) should provide funding to enable social skills training for people with ASD to be delivered at a local level. This training could be delivered by local authorities (through the hubs or through existing job preparation programmes) or by third-sector organisations.

2. Employers and support in the workplace

2.1 Local authorities should work to raise awareness among local employers; this includes building links with local groups and forums.

2.2 The Equality and Human Rights Commission (EHRC) should publish guidance on the reasonable adjustments employers should make when interviewing a person with ASD and adjustments they must make to the workplace (including sensory considerations).

2.3 The DWP should provide funding for employers to deliver ASD awareness training to their employees.

2.4 The DWP should work at a national level with employer organisations such as the Employers' Forum on Disability to raise awareness of ASD.

2.5 The DWP must provide specific guidance to Access to Work advisors on the support that people with ASD may need.

2.6 The DWP must run a publicity campaign on Access to Work targeted at employers and people with ASD.

2.7 The DWP should develop a Quality Standard to indicate exemplary employers of people with ASD.

2.8 The DWP must issue a toolkit for employers on the best ways to support people with ASD in the workplace (this could include details on developing an ASD "passport" and mentoring schemes).

3. Higher Education/Further Education

3.1 Local authorities must monitor the success of transition planning by collecting data on children with ASD as they pass from school to higher/further education or employment.

3.2 Local authority transition planning should include a focus on work, including agreeing work goals with the young person and a plan on how these are to be achieved.

3.3 Local authorities should ensure that Connexions makes reasonable adjustments for people with ASD, including adjustments for sensory considerations.

3.4 DCSF should make sure that all children with ASD have the opportunity to undertake work experience placements.

3.5 The Department of Innovation Universities and Skills should issue a note clarifying that Disabled Students' Allowances can be used for social support as well as more traditional academic support.

4. Benefits, tax credits and financial security

4.1 The DWP must publish information about benefits, tax credits and pensions in accessible formats (including plain English and easy-read formats) and target an awareness campaign of available benefits to adults with ASD.

4.2 The DWP should ensure that all Jobcentre Plus and Pension, Disability and Carers Service decision-makers receive training in ASD.

4.3 The DWP should introduce mandatory training for any doctors contracted to carry out medical assessments for benefits.

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

4.5 The DWP should conduct qualitative research to determine if the benefits and tax credits system works for adults with ASD. The results should be used to inform changes to the benefits and tax credits system.

5. Training

This section discusses public awareness raising programmes, training and workforce issues.

A theme running throughout this strategy is that a key barrier for people with ASD to accessing the support they need and fulfilling their potential is a lack of awareness of ASD among the general public and a lack of training in ASD among professionals, front line staff and others who work with people with ASD. This section, in conjunction with appendix 2, will look in more detail at what this training means.

Vision: The general public is aware of and understands ASDs, with myths surrounding the condition addressed. All professionals who come into contact with people with ASD are suitably trained and have a particular understanding of the communication, sensory and access needs of adults with ASD.

This will mean that:

- the contribution that people with ASD can make to society is fully recognised by the public and employers
- the vulnerability of some adults with ASD is also fully recognised among the public and professionals
- those working in health, social care, employment, criminal justice and other agencies have relevant training appropriate to their level of responsibility and the amount of interaction they have with people with ASD, and that this training gives them understanding of the range of ASDs and the ability to respond appropriately to the needs of adults with an ASD and their families.
- training for professionals is accredited and supports best practice and available evidence, as well as social inclusion. It is competently delivered, has links with academia, and its impact is monitored and evaluated.

What things are like now

General Awareness: understanding among the general public of the characteristics of ASD and how this can affect behaviour is low, leading to intolerance, discrimination and isolation. In a survey by The National Autistic Society, 83% of individuals with Asperger syndrome felt strongly or very strongly that many of the problems they faced were a direct result of others not understanding them.

Awareness among professionals and workforce development: training in ASD and awareness of the condition among professionals that provide support to or come into contact with people with ASD is poor. E.g. 71% of local authorities do not think that care managers receive sufficient training in ASD in their initial professional training. This has the following consequences.

- A lack of understanding of ASD among community care assessors, FACS assessors and NHS Continuing Care assessors means that the needs of adults with ASD are not adequately assessed and, as a result, people with ASD fail to receive the necessary support.
- Most GPs do not feel that they have sufficient information to screen people for ASD, with the result that people with ASD are not referred for diagnosis or signposted to appropriate support services
- As a result of low awareness of ASD, and Asperger syndrome in particular, among mental health professionals, misdiagnosis and inappropriate treatment (i.e. medication or therapy) are regularly reported.
- People with ASD are unable to access the support they need to find and keep a job, meaning that only 15% are in full-time employment.
- Without a trained workforce, the needs of people with ASD are misunderstood. Often this can lead to inappropriate contact with the criminal justice system or costly mental health services.
- Criminal justice system professionals and workers generally have a poor understanding of ASDs and very few reasonable adjustments are made for people with ASD who engage with the system as victims, witnesses or offenders.

Key Recommendations

1. Training

1.1. The following groups have been identified as needing greater awareness of ASD or needing to receive specific training in ASD.

Healthcare: including GPs, psychiatrists, psychologists, other mental health staff, nurses, NHS Continuing Care Assessors, speech and language therapists, occupational therapists, PCT commissioners, inspectors.

Social care: including social workers, community care assessors, FACS assessors, personal assistants, local authority commissioners, advocates (including IMCAs), social care brokers, social care support staff, those working in short breaks, care providers, inspectors.

Employment: including all DWP, local authority staff and others with responsibility for supporting people to find a job (such as Disability Employment Advisors, Jobcentre Plus Staff, work capability assessors, decision-makers, Connexions staff, specialist employment agencies).

Housing: including housing officers, registered social landlords, housing providers, housing associations.

Criminal justice and related agencies: including police, magistrates, prison and probation staff and appropriate adults.

Adult education: including further education, higher education and lifelong learning teachers, disability support advisors at colleges and universities and learning support staff

Benefits: including assessors for eligibility of benefits (both for individuals with ASD and their family carers) and benefit advisors.

Other groups, such as employers, colleagues of people with ASD, those working in public transport, staff working in banks and other financial institutions, the emergency services, leisure service staff and retailers were also identified as needing high-quality awareness training.

Within these groups, different levels of training will be required for different individuals dependent on their level of responsibility, their role and their likely degree of involvement with people with ASD.

Appendix 2 gives guidance about who needs training in ASD and at what level this training should be.

Local actions on training

1.2 Local authorities and PCTs should carry out an audit of the current training programmes in their area and workforce development programmes in relation to ASD to inform the development of an ASD training strategy. This should be done in conjunction with the independent sector in cases where they are involved in the delivery of ASD services.

1.3 Local training strategies should consider how specialist expertise in ASD, available locally, can be used strategically by commissioners to develop the competence of local and mainstream services. Protocols should be developed for mentoring between services to ensure that expertise is shared within a local area. This process should be used to cascade awareness training, peer support and good local practice across local authority, PCT and other relevant services in the community (including housing, Jobcentre Plus, Connexions, local employers, local leisure services, local retailers, local financial institutions and the police). People with ASD and their families should play a key role in this process.

1.4 Cascading expertise and awareness will be an important role for the new local ASD hubs, once established, who will have responsibility for providing support for mainstream services on ASD, raising awareness of the condition and training for health and social care staff and the wider community.

1.5 Training strategies should also ensure that the commissioners receive training to support them in commissioning appropriate services.

1.6 Local authorities should ensure that training is available on how to deliver social skills training to adults with ASD.

1.7 Local authority and PCT training programmes should be open to those working in the third and independent sectors and should be open to personal assistants.

1.8 Local authorities and PCTs should ensure that people with ASD and their families are involved in the design and delivery of training programmes and are properly remunerated for their involvement.

1.9 Local authorities and PCTs must ensure that those carrying out Community Care Assessments, FACS assessments or NHS Continuing Care Assessments receive specific training in ASD. Where staff have not yet received training, staff carrying out assessments should seek assistance from local partners (such as third-sector organisations) with expertise in ASD. A similar arrangement must be in place for social care brokers. Assessments must not be carried out by an assessor who does not have the necessary training, unless they are properly supported by input from third parties.

1.10 Local authorities should ensure that all social care workers and managers within social care services for people with ASD complete the “Introduction to supporting people who have an autistic spectrum condition” unit from the QCF, or an appropriate equivalent, as part of their induction training.

Regional actions on training

1.11 Government offices, SHAs and regional ASD teams should provide support to local authorities and PCTs and to local ASD hubs as they develop training and workforce plans.

National actions on training

1.12 The Department of Health should host a high-level national training summit, bringing together all relevant agencies from health and social care and partner organisations, to examine the best ways to improve training and workforce capacity in relation to ASD, including the development of specialist expertise in ASD in a range of sectors.

1.13 The Department of Health should issue guidance on promoting the involvement of people with ASD and family carers in all aspects of local, regional and national workforce planning and delivery.

1.14 The Department of Health must work with relevant agencies and bodies to support the development of standards for accreditation of appropriate tiered training programmes and clear pathways of training to develop expertise. The accreditation programme should be independent, transparent and inclusive.

1.15 The Department of Health should work with the CQC and other relevant partners to develop standards for monitoring the adequacy of training of staff during the inspection process.

National actions on social care training

1.16 The Department of Health must ensure that the needs of adults with ASD are taken into account in the implementation of the Adult Social Care Workforce Strategy. Among other things, this work must include looking at the training needs of personal assistants to be employed directly by an individual under personal/individual budgets.

1.17 The Department of Health must work with those with responsibility for the provision and regulation of undergraduate and postgraduate social work training to ensure that their curricula include mandatory training in ASD. Curricula should be competence-based and people with ASD must be involved in designing and providing the training. The Department of Health must ensure that all training in ASD becomes mandatory for approved social workers.

1.18 The Department of Health should instruct the new social work training taskforce to include recommendations on training in ASD in its review.

1.19 The Department of Health should ensure that the national advocacy qualification covers the needs of people with ASD and that people with ASD are involved in its delivery.

1.20 Skills for Care should build on its work in developing a knowledge set on ASD to develop higher level units on ASD.

National actions on training for healthcare staff

1.21 The Department of Health should ensure that the NHS “Welcoming Patients with Disabilities” training includes ASD.

1.22 Workforce development plans within the NHS must look at the training needs of all health professionals in relation to ASD, but pay particular attention to the development of specialist speech and language therapists, occupational therapists (including occupational therapists with particular expertise in sensory processing differences) mental health professionals and GPs.

1.23 The Department of Health must work with those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training to ensure that curricula include mandatory training in ASD. Curricula should be competence-based and people with ASD must be involved in designing and providing the training.

1.24 Psychiatric training must include experience in the diagnosis, assessment and management of individuals with ASD. In particular, there should be some

supervised experience with adolescents and adults of typical cognitive ability who have these disorders, as part of the training and continuing development for psychiatrists.

1.25 The Department of Health should work with professional regulatory bodies and education bodies to ensure awareness of the needs of people with ASD is incorporated into training for all of those working in healthcare.

National actions on training for organisations involved in employment

1.26 Jobcentre Plus must introduce mandatory training for Disability Employment Advisors and others involved in supporting people with an ASD to find a job (including work capability assessors and decision-makers).

1.27 Jobcentre Plus should ensure that its equality and diversity training includes specific training in meeting the needs of people with ASD.

1.28 The DWP should ensure that those assessing individuals for entitlement to benefits have adequate training in ASD.

1.29 The DWP should encourage employers to include the needs of people with ASD in their diversity and equality training and produce supportive materials to support this.

National actions on training in other areas

1.30 The DIUS should ensure that training of Disability Support Officers in further and higher education settings includes training in ASD and provide materials and guidance to support this.

1.31 The Learning and Skills Council (LSC) and any other organisation that takes on the LSC's duties should ensure that every further education provider has access to specialist support for students with ASD.

1.32 The Financial Services Authority (FSA) should build on its work on financial capability and ensure that the needs of people with ASD are fully incorporated within this.

1.33 The Home Office and the Ministry of Justice should work with the agencies they are responsible for to improve awareness and training in ASD. This will include working to ensure that equality and diversity training for all of those working in the criminal justice system includes awareness of ASD.

2. Awareness raising

Local actions on awareness-raising

2.1 Local authorities and PCTs should raise local public awareness on ASD through campaigns and events developed in partnership with relevant user-led

organisations, other third-sector organisations and local people with ASD and their families. New local ASD hubs would have a clear leadership role in developing campaigns and events.

2.2 Local authorities should work in partnership with local Jobcentre Plus to raise awareness of ASD amongst local employers.

2.3 The Home Office and the Ministry of Justice should encourage local police forces, local magistrates and others involved in the criminal justice system to engage with third-sector organisations to develop awareness-raising initiatives, such as ASD alert cards, that have been developed in some areas.

National actions on awareness-raising

2.4 The Department of Health should fund a national awareness campaign on ASD, which will include developing positive images of ASD. This could be delivered by one or more third-sector organisations.

2.5 The Department of Health should fund an ASD awareness DVD to be distributed widely to those working in health and social care. This should be supported by a website information programme and other materials. It should be accessible to people whose first language is not English.

2.6 The FSA should hold a high-level summit of retail bankers and others in the financial services industry to raise awareness of ASD. This should result in the development of a Code of Practice for the financial services sector on working with adults with ASD.

2.7 The DWP should work at a national level with employer organisations such as Employers' Forum on Disability to raise awareness amongst potential employers of how employing people with ASD might benefit their business, and what actual adjustments might be needed to support them.

Appendix 1: Local ASD hubs

A local multidisciplinary/ multi-agency team or “hub” will be set up in every local area (ideally for every 450,000 - 600,000 population).

The hub, jointly commissioned and funded by PCTs and local authorities, would sit in either the PCT or in the local authority services, depending on where there is the most expertise, or in the Care Trust where one has been established. Strategic leads and commissioners from both the PCT and the local authority should be involved. Each local hub will also part of a network of local services all linked to a regional specialist team.

The hub will have the following areas of responsibility.

- Skills/needs-based multidisciplinary assessment, diagnosis and re-assessment of adults with ASD, which leads to a personalised package of care.
- Post-diagnostic education and support for individuals with ASD and their family/carers.
- Signposting to mainstream services and support for the individual to navigate those services.
- Support for/ liaison with mainstream services to support the delivery of a personalised care plan.
- Liaison with children’s services to support transition and to ensure that information about an individual is not lost once they reach adulthood.
- Ensuring, in collaboration with local partners, the provision of low-cost, high-impact services (including social support and outreach), to all people with ASD, regardless of whether they are eligible for support through FACS.
- Ensuring the provision of care brokerage and facilitating the development of a person-centred care package for people with ASD and monitoring its effectiveness, where this cannot be provided elsewhere (e.g. through learning disability, mental health, vulnerable adult teams). This will be a particularly important role within the context of the move to personal/individual budgets.
- Outreach services.
- Signposting to advocacy services.
- Training for professionals in mainstream services, supported by the involvement of people with ASD and their carers.
- Awareness-raising of ASD among local groups of professionals and service providers, including employers, housing officers, education and leisure services and local health services.
- Monitoring need and developing ways to collate anonymous information on the number of people with ASD within the local area. This information will inform service planning and commissioning.
- Involvement of people with ASD, their families and user-led organisations and other relevant third-sector organisations in service development.

Members of the hub will include full-time, part-time and attached staff and trainees from a wide variety of backgrounds, as well as people with ASD and their families, including the following.

- Local ASD leads
- Social workers and community support workers
- Psychiatrists
- Psychologists
- Occupational therapists
- Speech and language therapists
- Community nurses
- Access for specialists for referral (e.g. to physiotherapy, dieticians, sensory occupational therapists,)
- People with ASD
- The families/carers of people with ASD
- Representatives from third-sector organisations (including user-led organisations).

The team will need to build up strong links and networks with individuals with ASD and their families, local authority teams (including learning disability teams, mental health teams and housing teams) , local health and mental health services (including secondary mental health services), Connexions, Jobcentre Plus, third-sector organisations and independent providers.

People with ASD must be involved in the establishment of these teams.

While the hub will be a core of expertise on ASD, its existence will not reduce the responsibility that other agencies and teams have for people with ASD. These responsibilities must be maintained. The hub will however be able to offer support through training and exchanging of expertise to these other agencies and teams.

Appendix 2: Training Requirements

Agency	Profession/job (Examples of)	Role (Examples of)	Autism awareness	Induction Level 1	Intermediate Level 2	Advanced Level 3	Specialist Level 4
1. Health	1. Agency wide	Healthcare provision and health promotion	E	E	E	E	E
	2. GP	Health care Promotion and treatment	E	E	D	D	
	3. GP	Special assessor	E	E	E	E	E Diag and Ass
	4. Adult psychiatrist	Diagnosis assm'nt and treatment	E	E	D	D	E Diag and Assm'nt -co morbidities
	5. SALT		E	E	D	D	D
	6. Nurse – general/district	Medical care	E	D			
	7. Nurse LD	Behaviour and other support	E	E	E	D	
	8. Nurse Mental Health.		E	E	E	D	E if CPN
	9. OT		E	E	D		
	10. OT	Sensory assessment	E	E	E	E	E If undertaking sensory ass in ASD
	11. Psychologist clinical	Diag and assm'nt-intervention	E	E	E	E	E

	12. Psychotherapist	Treatment	E	E	E	E	E
	13. Therapist (e.g. behaviour, family etc)	Treatment and support	E	E	E	E	E
	14. dietician	Nutritional advice	E	D			E if undertaking specialist work with ASD
	15. Other specialist professional	Various health and related	E	D			
2. Social care	16. Agency wide	Provision of social care and support services	E	E	E	E	E
	17. Partnership boards	Strategy and services	E	E	E	D	
	18. Social worker	Assessment Support	E	E	E	D	D (E) if assessment
	19. Senior manager	Allocation of resources	E	E	D		
	20. Care manager	Placement and services	E	E	D		
	21. Support worker	Support in services	E	E	E	D	D
	22. Service manager	Registered manager	E	E	E	E	E
	23. Befriender	Informal befriending	E	E	D		
	24. Community teams	Support for individuals	E	E	D		

	25. Mentor		E	E	D	D	E
	26. Personal assistant	Home support	E	E	E	D	
	27. Administrator (e.g. contracts)		D				
3. Criminal justice related	28. Agency wide Dept of justice and Home Office	Administration of justice	E	E	E	E	E
	29. Police force	Victim support Crime prevention Investigation Prosecution	E	E	D	D	
	30. Senior police officers		E	D	D		
	31. Police officers	On street contact Victim support	E	D			
	32. Appropriate adult	Protection and support Victim support	E	E	D	D	
	33. Custody sergeant	reception	E	E	D		
	34. CPS	Decisions on prosecution	E	D			
	35. Magistrates and judiciary		E	D			
	36. Probation staff	Pre-trial and aftercare support	E	E	D		

	37. Courts staff	Conduct of the court	E				
	38. Senior prison staff		E	D			
	39. Personal officers (prison)		E	E	D		
	40. Prison officers		E	D			
	41. Secure hospital staff	Nursing and associated	E	E	D		
	42. Prison / secure hospital therapists	e.g. CBT Anger mnmt etc	E	E	E	D	E e.g. if CBT or group interventions
	43. Prison/ secure hospital healthcare staff		E	E	D	D	
	44. Prison / secure hospital Psychology		E	E	E	D	
	45. Prison/ Secure hospital social worker	In reach and aftercare	E	E	E	D	
	46. Prison / secure hospital vocational staff		E	D	D		
	47. Forensic Psychiatrists	Specialist diagnosis assessment and support	E	E	E	E	E
	48. Police / secure hospital medical officer		E	E	D		

	49. Solicitors	Advocacy	E	D			
	50. Barristers	advocacy	E	D			
	51. Hostel staff		E	E	D		
	52. Prison religious	e.g. chaplain imam, priest	E	D			
	53. Parole boards		D				
4. Statutory Inspectorate	54. OFSTED 55. SQC	Inspectorate	E	E	E	E	
	56. Inspector	Inspection	E	E	E	D	
5. Adult Education	57. Continuing education	Higher and continuing education and training	E	E	D	D	
	58. Senior staff and management		E	D			
	59. Lecturer	tutor	E	E	D	D	
	60. Counsellor	mentoring	E	E	E	D	E
	61. Student welfare officer	Student welfare	E	E	D	D	D
6. Benefits Employment, and vocational	62. Agency wide	Benefits Employment and related services					

	63. Benefits agency staff	Entitlement and adjudication on eligibility e.g. DLA etc	E	D E if assessor	D E if assessor	D	
	64. Job centre staff		E	D E if assessor	D E if assessor		
	65. DEA		E	E	D		
	66. Manager job centre		E	E	D		
	67. Connexions staff		E	E	D		
	68. Employers of people with ASD		E	D	D		
	69. Specialist emp. Agencies	Work for people with ASD	E	E	E	D	E
Day service staff	70. Vocational and occupational	E	E	E	D	D	Day service staff
7. Emergency services	71. Police 72. Fire Service 73. Ambulance	Emergency response	D				
8. MISC.	74. Advocates	Citizen advocacy	E	E	E	D	D
	75. Leisure services and retail		D	D			
	76. Financial institutions		D				
	77. Social group		E	E	D	D	

	leader						
	78. Volunteer co ordinator		E	E	D	D	
	79. Relevant politicians	Elected members of LA e.g. relevant committees	D	D			
	80. Citizens advice staff		D				
	81. Samaritans	Emergency counselling	E	D			

E= Essential

D= Desirable

Key

level	Outline of content	Possible medium/means for delivery	status
Autism Awareness (AA)	Key features of autism and basic facts on the numbers, causes and characteristics of ASC How to respond to someone with autism 'Do's and don'ts' Personal perspectives Family perspectives Sensory issues	5-10 minute web/ DVD and discussion. Will need to be produced Leaflets Website	Quality control and content to be agreed Huge demand potentially – web based materials to be developed
1. Induction	Builds on Autism Awareness Historical context of autism Ethics, Values and inclusive practice Expansion of key points from AA Introduction to key principles of intervention. Individualised practice. Impact on individuals and families	One half day course instruction and discussion. Group and individual work e.g. SPELL induction. Autism Focus	Continuing Professional Development (CPD) model and skills frameworks? Content will need to be guided to meet agreed criteria Build capacity to deliver much content already exists but need to be audited for consistency
2. Intermediate	Builds on above Practical application of principles Ethics and safeguards Methods of intervention and models of services	CPD model Series of workshops to be agreed – theory and practice – bespoke and local models plus established frameworks e.g. TEACCH / SPELL 1 and 3 (NAS and Tizard Centre)	As above Formal evaluation /accreditation of training at this level. Impact and content. CPD credits Build capacity to deliver but much content already in place
3. Advanced	Application of theory at more advanced level – research or evidence based practice – analysis of behaviours and interventions. Refreshment of practice- new ideas – challenging prevailing ideas and concepts. Epistemological dimensions. Reflection. Research.	CPD – building on previous model Expert trainers – consistent message. Mentors Degree and cert level courses e.g. B'ham University	Quality control through formal evaluation and accreditation of courses and learning. CPD credits Build capacity to deliver but much content already in place
4. Specialist	Leading interventions and practice e.g. diagnosis and assessment specialist behavioural or psychopharmacological interventions	Access to specialist training in key areas e.g. ADOS, ADI, DISCO, Dunn profile, other psychometrics, assessment TRIAD, Risk - RAMAS etc etc	Accredited training and instruments and formal controls essential Capacity already exists but may need refinement

Appendix 3: Other issues that arose in the ERG discussions

Criminal justice system: It was felt by the group that further work was needed on improving the criminal justice system to better support people with ASD and ensure they were not inappropriately detained, whether they were victims, offenders or witnesses. In particular, issues were raised about the training of those in the criminal justice system and the need to make reasonable adjustments. The ERG hopes that this can be explored further as the consultation progresses.

Issues about portability of support packages: Independent living should also be about being able to live where you want to live in the country. While ordinary residence rules restrict this, it is not an ASD-specific issue, but still needs to be raised.

Travel passes: Although not an ASD-specific issue, there were calls for some in the group for the development of “Companion Passes” for support workers who travel with people with ASD who cannot travel alone.

Use of the term ‘autism spectrum disorder’: The most widely-used term is currently ‘autism spectrum disorder (ASD)’. Others use ‘autism spectrum condition (ASC)’. The autism rights movement uses ‘autism spectrum difference (ASD)’. Some members of the group felt the use of these terms needed to be explored further, but this was precluded by lack of time.

Recognition of the autism rights movement and autistic culture: Some members of the group sought recognition in the strategy for autistic culture and the autism rights movement.

Metabolic issues: There was discussion about food intolerances among people with ASD and the need to take action to make gluten-free and casein-free food made cheaper. It was also proposed that these two ingredients be removed from the coating of medications.

International Accessibility Standards: There was some discussion about the need for the Government to work with the EU and at international level to look at the accessibility of international transport.