

think  
differently  
about  
autism



A better future:  
consultation response  
from The National  
Autistic Society

September 2009

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*This response is supplemented by:*

- 1. A supplementary response from Prospects, NAS' specialist employment service*
- 2. The NAS' good practice guide*

## About us

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism<sup>1</sup>. We were founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. Today we have over 18,000 members, 80 branches and provide:

- information, advice, advocacy, training and support for individuals and their families information and training for health, education and other professionals working with people with autism and their families
- specialist residential, supported living, outreach and day services for adults
- specialist schools and education outreach services for children
- out-of-school services for children and young people
- employment training support and social programmes for adults with autism.

A local charity with a national presence, we campaign and lobby for lasting positive change for those affected by autism in England, Wales, Scotland and Northern Ireland.

We warmly welcome the introduction of a national strategy for adults with autism, and are grateful for the opportunity to respond to the consultation. This response draws extensively on our *I Exist* survey of 1,400 people in England with autism and their families, published in 2008.

A large part of this research looked at the experiences of people with autism in accessing social care and of the services they received, as well as other issues included in the consultation paper, including employment, housing and independent living. In preparing for this response, the NAS also carried out focus group sessions with adults with autism, carers and professionals.

*This response is submitted in conjunction with the NAS' new Good Practice Guide, which includes examples of good and innovative practice from across the UK.*

## About autism

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty are:

- **difficulty with social interaction.** This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships
- **difficulty with social communication.** This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice

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<sup>1</sup> The term autism is used throughout this document to refer to all people on the autism spectrum including Kanner autism, Asperger Syndrome and high-functioning autism.

- **difficulty with social imagination.** This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds touch, tastes, smells, light or colours. Asperger syndrome is a form of autism.

Research has shown that 1 in 100 children has autism. Very little is known about how many adults have autism, but by applying the 1 in 100 figure we estimate that over 300,000 adults in England have autism. Together with their families, they make up over one million people whose lives are touched by autism every day.

### **The case for improvement**

Unfortunately, many of these people face a huge challenge as they try to access much-needed services.

Our research<sup>2</sup> found that 63% of adults with autism do not have enough support to meet their needs. As a result 61% rely on their families for financial support, over 40% live with their parents and only 15% are in full-time employment.

44% of those who live in their own flat or house say that their family provides most of their support. 92% of parents are either very worried or quite worried about their son or daughters future when they are no longer able to support them. It is important that the Strategy recognises the central role that many families play in supporting adults with autism, and that its recommendations take account of this wider context.

45% of local authorities have no process for supporting adults with autism who do not have a learning disability or mental health problem. 98% of local authorities and 100% of Primary Care Trusts (PCTs) want more Government support to deliver services for adults with autism.

This year the National Audit Office published the findings of research<sup>3</sup> they conducted on public spending on autism. They found alarming gaps in training, planning and provision that not only dramatically reduce quality of life for adults with autism but in fact waste public money through their inefficiency.

Both *I Exist* and the NAO's report will be explored in greater detail throughout this response.

The recommendations in this response generally apply to adults across the autism spectrum. In some instances we discuss the specific barriers that those with Asperger syndrome or High Functioning Autism face when trying to access services. However, this does not reflect a belief that adults with autism who have a learning disability or a

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<sup>2</sup> Rosenblatt, Mia. (2008) *I Exist: The message from adults with autism in England*. London: The National Autistic Society

<sup>3</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

diagnosis of 'classic' or 'Kanner' autism are receiving adequate support. On the contrary the NAS recognises that adults with autism who receive learning disability or mental health services are not necessarily accessing appropriate or adequate support. Moreover, many are not accessing a service at all. Our research found that almost half (47%) of parents and carers of adults with autism who have an accompanying learning disability are entirely reliant on their parents for support, and for those who are able to access services, these often do not take account of their autism and can therefore be inappropriate and potentially damaging.

**For more information about anything written in this response, please contact**

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## **Summary of priority actions**

The National Autistic Society believes that the delivery of an effective strategy to improve life outcomes for adults with autism will be dependent upon it including the following key actions.

### **1. A Specialist Autism Team in every local authority / PCT partnership**

A Specialist Autism Team (SAT) must be established within every local authority / PCT partnership. The SAT would provide autism expertise, including diagnostic services, at a local level, while building capacity around autism in mainstream services. It would be jointly funded and delivered by health and social care. Its principle functions would be to:

- provide a diagnostic service and post-diagnostic support, establishing a referral pathway for diagnosis and support
- provide an ongoing programme of training to frontline staff across health and social care
- support social services with care assessments in more complex cases
- provide sign-posting and brokerage to help adults with autism find appropriate services
- provide a range of 'low level' services and interventions aimed at reducing social exclusion, promoting well-being and improving employment prospects
- build local capacity around employing adults with autism.

### **2. An Autism Planning Group in every local authority / PCT partnership**

An Autism Planning Group must be set up within each locality to ensure that appropriate services are developed locally through effective joined-up planning and commissioning.

The APG would:

- develop, through intelligent planning and commissioning, appropriate services to meet the needs of the local autism population
- use existing data-sources and proactive measures to lead the way on local data collection and identification
- feed into the Joint Strategic Needs Assessment process
- be made up of learning disability and mental health commissioners and managers, representative(s) from the SAT, representatives from the voluntary sector, adults with autism and carers, and a representative from children's services
- be chaired by a commissioner with joint responsibility for commissioning health and social care services.

### **3. Clear structures for reporting and delivery**

Reporting and delivery structures must be established with the right balance of seniority and work-load capacity at national, regional and local government levels.

At a national level we recommend:

- The appointment of a full-time senior civil servant and support to handle workload capacity
- A cross-Departmental steering group, meeting regularly
- The External Reference Group being retained in some form

At a regional level we recommend:

- Deputy Regional Directors within Government Offices having ultimate responsibility for regional delivery
- One member of Regional Government Office staff appointed as Regional Autism Lead
- Regional Autism Planning Groups established to share good practice and commission at a regional level where appropriate

At a local level we recommend:

- A local autism lead appointed, with responsibility for local implementation of the strategy, ideally a senior commissioner with responsibilities across health and social care
- A local Autism Planning Group established (see above) chaired by the local autism lead
- The local autism lead to report to the Director of Adult Social Services, who has ultimate responsibility for delivery of the strategy
- A Specialist Autism Team established (see above) reporting to the local autism lead.

#### **4. Clear methods for inspection and evaluation**

The Department of Health must establish clear means by which to monitor and evaluate the implementation of the strategy at all levels, by doing the following:

- CQC inspectors must have the training and expertise to assess outcomes for adults with autism. DH must produce guidance to support this.
- DH, working in partnership with the Department of Communities and Local Government and the Cabinet Office, must develop National Indicators on local outcomes for adults with autism.
- DH should task CQC with carrying out a thematic review into implementation of the strategy on the first or second anniversary of its introduction, to ensure that progress is monitored from the start.

The strategy must, as has already been committed by Government, be accompanied by robust statutory guidance for local authorities and PCTs to ensure delivery.

#### **5. Sufficient levels of funding allocated**

Although it has been established that spending money on services for adults with autism will save public money in the medium- to long-term, a significant initial outlay of funding will be required for the strategy to be implemented. Without this funding the

strategy can only hope to make a relatively minor difference to outcomes for adults with autism.

## **6. Priority actions from each of the five chapters**

### Social inclusion

- Social care needs assessments must be carried out by an appropriately autism-trained professional who has a good understanding of the nature of autism in order to assess their needs properly and fairly
- The Autism Planning Group must take proactive steps to identify adults with autism currently unknown to services
- The strategy must put a specific requirement on local authority / PCT partnerships to include the needs of adults with autism in their Joint Strategic Needs Assessments
- Preventative and low-level services must be prioritised by commissioners

### Health

- Adult diagnostic services must be made available at a local level, within the SAT
- Comprehensive, transparent referral pathways for diagnosis and support must be established at a local level
- The remit of the NICE guidance on diagnosing autism in children must be extended to include diagnosis of adults
- Sufficient training must be given to all frontline healthcare professionals, including mental health professionals, such that they can a) recognise signs of autism as part of the referral pathway, and b) better manage their patients with autism

### Choice and control

- Resource allocation for individual/personal budgets, however it is determined, must take into account the additional costs associated with support for adults with autism and complex needs, and must include brokerage costs
- The APG must ensure that appropriate services are available locally to reflect the support that individuals wish to buy with their personal/individual budgets and direct payments
- Statutory duties around transition must be extended to include all children with autism supported through School Action Plus
- Appropriately autism-trained advocates must be made available to all adults with autism and must be free for the individual to access
- The strategy must emphasise the need for public bodies to specifically involve people with autism, their families and carers, in meeting their responsibilities under the DED. Any consultation documents or events must be fully accessible to people with autism.

### Access to training and employment

- Autism Coordinators must be introduced to ensure that there is a clear source of autism information and advice available to all Jobcentre staff, to increase awareness among local employers and to join up existing autism services within an area. They

would work closely with Specialist Autism Teams, who would themselves have an employment focus.

- All existing Disability Employment Advisers who did not receive autism training on starting the job should be given the new training as a priority. Personal advisers must also be trained to this level.
- The strategy must make clear that staff in Jobcentre Plus must inform adults with autism of their right to an advocate at the start of the benefits assessment process
- Transition plans for young people with autism must have an employment focus, including seeking opportunities for work experience.

### Training and awareness

- Autism training for key professionals in health, social care and employment services must be included in initial professional training syllabuses
- Local APGs must develop and deliver a training strategy at a local level to identify skills and knowledge gaps among professionals and commission training appropriately
- A cross-Departmental national training strategy must be developed and delivered to ensure that all staff whose roles impact upon adults with autism are given an appropriate and proportionate level of training.
- DH must fund a high-profile awareness raising campaign aimed at challenging stereotypes and increasing understanding of autism among the general population

All of our recommendations are listed throughout this document, and are listed in full at the end of the response.

## **Specialist Autism Teams and Autism Planning Groups**

### **A) The Specialist Autism Team (SAT)**

*“Our county council heavily focuses its support towards learning and physical disability. The authority’s social services refuse to support or even acknowledge Asperger syndrome as a unique disability requiring specialist intervention.”* Adult with autism

The evidence cited in the introduction and throughout this response highlights the extremely poor outcomes for adults with autism and demonstrates the need for vastly improved local provision for adults with autism. Frontline staff, be it General Practitioners, mental health professionals or social workers, lack the skills and knowledge to provide satisfactory support. Inadequate or non-existent autism training means such professionals do not have the expertise to adapt their service to meet the needs of adults with autism. The result is a system that routinely fails this group at all stages from identification and diagnosis through to care planning and provision.

The National Audit Office found that only 10% of local authorities and PCTs commission ongoing support for people with Asperger syndrome (AS) and high-functioning autism (HFA). The evidence strongly points towards the need to set up a Specialist Autism Team (SAT) within every local authority / PCT boundary. This team would ensure that expertise is available locally, that mainstream services are better trained and equipped to support adults with autism and that autism provision is championed in every locality. Without such a team, we have serious concerns that the strategy would fail to generate real progress in terms of better outcomes for adults with autism.

#### **What would the SAT do?**

*“Obstacles are still around. Where do they fit - learning disability or mental health? It would help to have an Asperger syndrome or ASD-specific service or team.”* Local authority

The NAS recommends that the SAT has a very clear remit and stated objectives to improve provision for adults with autism. It would provide the specialist expertise that does not currently exist in mental health and learning disability services.

The SAT would not be a service just for adults with AS and HFA, but would be tasked with improving provision for adults across the whole autism spectrum. Outcomes are poor for adults with autism, whether they are ‘high-functioning’ or have a learning disability, and the autism team must aim to better these outcomes for adults wherever they are on the spectrum.

However, it would not become a ‘one stop shop’ for everything autism-related, and its formation must not create a local culture in which mainstream services feel they can pass all responsibilities relating to adults with autism over to the SAT and waive their own responsibilities. This would *not* be the purpose of the SAT. Indeed, the opposite is true in that perhaps the most significant function of the SAT lies in building capacity for supporting adults with autism within mainstream services.

So it is important to make absolutely clear what the role of the SAT would be and what functions they would and would not be expected to carry out. These functions would be:

1. Provide a diagnostic service and post-diagnostic support, establishing a referral pathway for diagnosis and support
2. Provide an ongoing programme of training to frontline staff across health and social care
3. Support social services with care assessments in more complex cases
4. Ensure that sign-posting and brokerage is available to help adults with autism find appropriate services
5. Provide a range of 'low level' services and interventions aimed at reducing social exclusion, promoting well-being and improving employment prospects
6. Build local capacity around employing adults with autism

### 1. Provide a diagnostic service and post-diagnostic support

There is an alarming lack of diagnostic services for adults across the country and for many adults with autism accessing a diagnostic service can seem impossible. It is crucial that diagnostic services are available at a local level. Many adults with autism will never get a formal diagnosis. Our research found that 48% of PCTs do not have an autism specialist diagnostic service or an identified person who can undertake assessment within their locality. Those PCTs that told us that they can undertake assessments within their boundary often offer a limited service, not of a specialist nature.

Although eligibility for support should always be based on the needs of the individual and not diagnosis, we have found that this is not always the case. In fact, 54% of local authorities believe that adults with autism who have a diagnosis are more likely to receive support than those without one. Furthermore, a full, multi-agency diagnosis, including assessment of the individual's skills and impairments, acts as a valuable part of a social care needs assessment. Therefore it can be concluded that a lack of diagnostic services is a major factor in adults with autism failing to receive the support that they need.

Because of the scarcity of diagnostic services, when people do manage to get a referral for diagnosis it will more often than not be for a service that is out of area and subject to a lengthy waiting list. Consequently, the individual will often return to their local authority with a diagnosis of autism but will find it impossible to access the post-diagnostic support they require.

An SAT will provide both diagnostic and post-diagnostic services in every local area. Therefore many more adults with autism will be able to quickly and locally access a diagnosis after referral. Post-diagnostic support from the SAT will mean that they will not be left isolated, confused and unsupported after diagnosis, but will be given the post-diagnostic support they need from the same local service. The SAT must also establish a clear and transparent referral pathway for diagnosis and support to compliment this work.

*More on diagnosis, post-diagnostic support and referral pathways can be found in the Health chapter.*

## 2. Provide an ongoing programme of training to frontline staff across health and social care

Autism training and awareness in frontline professionals is at unacceptably low levels. Our research found that local authorities do not think that care managers receive sufficient training in autism in their initial professional training (71%) or in their ongoing professional training (67%)<sup>4</sup>. Similarly, the NAO found that only 29% of local authorities' training programmes for staff who carry out Fair Access to Care Services (FACS) assessments covered high-functioning autism. The NAO also found that 80% of GPs feel that they need additional guidance and training to manage patients with autism more effectively<sup>5</sup>.

Clearly the SAT would not be expected to, nor would it have the capacity to, take on the case-load for all adults with autism in their area, nor directly conduct community care assessments. Therefore, one of the principle roles of the SAT would be in building capacity among existing services and professionals to better support adults with autism.

The SAT would support the delivery of a local training programme. The training programme would aim to ensure that frontline staff working with adults with autism are well equipped to support adults with autism. Staff from mental health and learning disability teams who carry out community care and FACS assessments would be prioritised.

The training programme would also seek to improve the ability of frontline staff to recognise autism and make appropriate referrals for diagnosis back to the SAT. Lower levels of autism awareness training would also be rolled out to other professionals whose roles may impact upon adults with autism.

*More on training can be found in the Training chapter.*

## 3. Support social services with care assessments in more complex cases

Care assessments will remain the responsibility of mainstream social care assessors. The primary role of the SAT with regard to care assessments will be to train assessors to better understand and assess the needs of adults with autism, as discussed above.

However, for some individuals with autism and more complex needs the SAT would have another function, that being to provide direct support with assessments where needed. For individuals for whom social services do not have sufficient expertise to carry out an appropriate assessment, the SAT would accompany the assessor to support the assessment process. This would have the dual outcome of ensuring that the individual gets a fair assessment, as well as training the mainstream assessor who is able to learn by experience.

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<sup>4</sup> Rosenblatt, Mia. (2008) *I Exist: The message from adults with autism in England*. London: The National Autistic Society

<sup>5</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

The SAT would also take on a ‘trouble shooting’ role, and could be called upon for advice and assistance when assessors need help with complex cases, for instance when a placement is not working out for an adult with autism.

*More on assessments can be found in the Social Inclusion chapter.*

#### 4. Ensure sign-posting and brokerage is available to help adults with autism find appropriate services

Adults with autism can find it very difficult to access appropriate services to spend direct payments and personal budgets on. For many people, the freedom to spend their social care budget how they wish is only a positive thing if they are supported to find appropriate services to meet their needs. Similarly, many adults with autism who fail to meet local authority eligibility criteria for support will need to be sign-posted to ‘low level’ services, such as support groups and social skills training.

The SAT would therefore have an important role to play in mapping existing services and helping adults with autism to find and access them.

*More on sign-posting and brokerage can be found in the Choice and Control chapter.*

#### 5. Provide a range of ‘low level’ services and interventions aimed at reducing social exclusion, promoting well-being and improving employment prospects

In many local authorities there are no or few ‘low level’ autism-specific services. These services are often very cheap to run but can have a huge impact on the lives of the people who access them, helping them to develop skills which can hugely benefit their quality of life.

As well as mapping existing autism services, as above, the SAT would deliver a range of ‘low level’ services to adults with autism. These services might include things such as social skills training, social groups and mobility training, but the precise nature and extent of these services would be dependent on local need.

The services delivered by the SAT would be autism-specific services and would be aimed at reducing social exclusion, promoting well-being and improving work-related skills. They would aim to reduce the likelihood of adults with autism developing needs which require contact with secondary mental health services or other services, as well as improving employment prospects. These services are likely to be aimed primarily at adults with HFA and AS.

*More on low-level service provision can be found in the Social Inclusion chapter.*

#### 6. Build local capacity around employing adults with autism

Improving employment outcomes for adults with autism must be integral to the remit of the SAT. Gaining paid employment is such a crucial part of tackling social exclusion for this group, as well as having obvious benefits for their health and well-being. Local authorities already have responsibilities around employment for adults with learning disabilities (through Valuing Employment Now) and for adults with mental ill health

(through the forthcoming mental health employment strategy) so these responsibilities must be extended to include adults with autism if this group is to not be left behind.

The SAT would have responsibility for building local understanding around the support that adults with autism need to find employment. This would include:

- building capacity in local authority employment services to better support adults with autism
- working with day/resource centres who work with adults with autism to support an employment focus in their programme
- training Connexions staff to enable them to effectively build employment support into transition plans
- training to ensure that person-centred planning for adults with autism, carried out by learning disability and mental health teams, includes an employment focus
- working with local authorities and PCTs to employ more adults with autism internally
- linking with Autism Coordinators<sup>6</sup> to support capacity building at Jobcentre Plus.

*More on employment support can be found in the Employment chapter.*

In summary, the SAT would help adults with autism to access a range of appropriate mainstream services while simultaneously improving the ability of these services to effectively support this group. In service delivery, its main purpose is in enabling mainstream services to work for people with autism, not in delivering those services as a team. The strategy must make this very clear to all involved in service delivery, such that those involved in delivering learning disability and mental health services understand that responsibility for enabling adults with autism to receive appropriate support will remain theirs in most instances.

### **Where would the SAT be located?**

The specialist team must be jointly commissioned by both health and social services teams. The remit of the team, as outlined above, includes both health and social care functions and it is essential that buy-in from both the PCT and the local authority is mandatory. A genuinely joined-up approach to funding and delivery is necessary for this team to successfully deliver.

### **How would the SAT be staffed?**

We would not wish for the strategy to be overly prescriptive over which and how many professionals were included in the SAT. Decisions of this nature will be best made at a local level, depending on the size of the population the team would be covering and the extent of local need.

However, for the team to be able to deliver the above functions certain staff members will be necessary. In order to deliver a diagnostic service the SAT must include an appropriately trained clinical psychologist/psychiatrist or equivalent. To deliver on brokerage, training and assessment support, the SAT must include an experienced social worker with autism expertise. And to deliver on employment-related activity, the

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<sup>6</sup> See Employment chapter from page 69

team must include a member of staff with expertise in improving employment prospects for adults with autism.

We envisage that in an average local authority / PCT area, the SAT will need a minimum of 4 or 5 full-time staff (or equivalent).

### **Why is this our favoured model?**

#### Competency gap in existing services

Frontline staff from mainstream services are consistently found to be lacking the skills, understanding and resources to provide satisfactory support to adults with autism. Many staff do not have the capacity to adapt their service to meet the needs of adults with autism, resulting in ineffective and inefficient interventions that routinely fail this group, and can even be harmful. This is demonstrated by the appalling outcomes for adults with autism, documented throughout this response.

There is widespread failure to identify adults with autism, to diagnose their autism, to provide appropriate assessments of need and to provide the right support. The NAS believes that a specialist team is the best way to ensure that this is addressed.

#### Many adults with autism ‘fall through the gaps’

*“When he was mentally ill I tried to get support from mental health services, but because he was on anti-psychotics and was quite stable they said it was nothing to do with them. The social services learning disability team told us that as his IQ was normal they couldn’t do anything for us. I was at my wits end, I couldn’t support him. But they said that he can do things like go to the shop, throw things in the frying pan and make food. We were told that the sort of people they look after couldn’t even find the frying pan.*

*“His mental health deteriorated to such an extent that he was sectioned by the police. He was in intensive care for nine months, he was extremely ill. I had written letters to social services saying this was going to happen.”*

Parent of an adult with autism

Over half of adults with autism do not have a learning disability, and most are unlikely to meet the eligibility criteria for secondary mental health services. Therefore, as a whole group, their needs extend beyond the remit of either service as they are currently set up. Our research revealed that over 60% of adults with Asperger Syndrome or high-functioning autism say that they have experienced difficulties in accessing services and 52% of these were told that they do not fit easily into mental health or learning disability services<sup>7</sup>. When we asked PCTs whether they have a process to support adults with

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<sup>7</sup> Rosenblatt, Mia. (2008) *I Exist: The message from adults with autism in England*. London: The National Autistic Society

autism who are not eligible for either learning disability or mental health services, 55% told us they do not.

A specialist team is needed to fill this gap in provision, such that those services that have previously turned adults with autism away will have the skills and capacity to offer them support. The SAT would also provide the kind of specialist support, such as 'low-level' services to combat social exclusion and sign-posting to existing autism services, which standard service structures are not currently provided under.

### Functional teams are a model successfully used by the Department of Health for other conditions

Department of Health policy in recent years has led to the creation of a range of functional teams within secondary mental health services. These include teams to deal with eating disorders and early intervention for psychosis, for example. This specialist provision has been a successful policy drive for the Government and is demonstrating good outcomes. It would seem sensible to extend this initiative to autism - another area in which a group with distinct needs is being failed due to a lack of specialist expertise.

### Based on current best practice, this is most effective model

The SAT model outlined above is based upon current best practice across England. Those few existing services that are consistently given high praise for their autism provision have done so through setting up local specialist autism teams. These teams are of variable sizes and capacities, but fundamentally they aim to deliver the core functions outlined above. The Nottingham and Liverpool good practice outlined in the attached Good Practice Guide demonstrate this.

## **B) The Autism Planning Group (APG)**

A failure to plan and commission services for adults with autism at a local level is another significant barrier to support. The National Audit Office found that 74% of local authorities do not have a commissioning strategy for adults with autism. Therefore this group are often expected to use learning disability or mental health services, which are often inappropriate either because the individual does not have a learning disability or mental ill health, or because the service is not autism-friendly.

*"It was more destructive being in a system with people who didn't know what they were doing than not being in the system at all."* Adult with Asperger syndrome

There is a major job to do across the country in terms of developing appropriate services for adults with autism through effective local planning and commissioning, and a specific group, the Autism Planning Group (APG), must be set up for this purpose in each locality.

### **What would be the remit and purpose of the APG?**

The APG would:

- develop and maintain, through intelligent planning and commissioning, appropriate services to meet the needs of the local autism population
- use existing data-sources and proactive measures to lead the way on local data collection and identification
- feed into the Joint Strategic Needs Assessment process
- be made up of learning disability and mental health commissioners and managers, representative(s) from the SAT, representatives from the voluntary sector, adults with autism and carers and a representative from children's services
- be chaired by a commissioner with joint responsibility for commissioning health and social care services

Further detail on the remit and purpose of the APG is as follows:

#### The APG will just be for adults and transition

The NAS is recommending that there must be an APG set up in each locality to focus on adult and transition issues. If the APG is set up to include children also, we would welcome this approach. However, it is important that if the APG does include children a sub-group is set up to deal specifically with adult and transition. This is because we would be concerned that without a specific adult focus some groups may not put enough emphasis on adult services.

Provision for children remains very patchy and we would welcome children's issues being covered by the APG, or a similar group being set up specifically for children's services. However, we feel strongly that there needs to be planning group, or sub-group, specifically for adults.

A representative from children's services should attend adult meetings to ensure good communication between departments.

#### The APG must not be a sub-group of learning disability partnership boards

The APG would report to the Director of Adult Social Services. It must *not* be a sub-group of the learning disability partnership board, but must have an equal status. Making this a sub-group of the learning disability partnership board would amount to prioritising learning disability over autism, whereas they must be considered of equal priority. If anything, as autism services are at a significantly less developed stage than learning disability services in the vast majority of local authorities, these are deserving of local priority. A sub-group also suggests that autism is a learning disability, which is not the case. It is important that those on the APG are able to take into account the needs of all people with autism including those without a learning disability, which is over 50%. There can be no justification for giving the APG a lesser standing than a learning disability partnership board.

#### The APG will lead the way on data collection and coordination

As part of its role, the APG would be expected to use existing data from multiple agencies to determine levels of demand and facilitate strategic transition planning. They would use data from Children and Young People's Plans, school statements and School Action Plus for example, to gauge numbers of children with autism coming up through

children's into adult services. It will also bring together data from other existing sources to form a good picture of the local autism population. The APG must also be proactive in identifying those who are not already known to services. This is explored further in the Social Inclusion chapter.

### Feed into Joint Strategic Needs Assessments

Research from the NAO found that only 21% of Joint Strategic Needs Assessments (JSNAs) included specific reference of autism<sup>8</sup>. As the key local strategic planning tool, if the JSNA does not involve the needs of adults with autism, sufficient appropriate services will not be commissioned. The APG will ensure that data is collected and co-ordinated effectively to inform the JSNA and ensure that the needs of adults with autism are fully and intelligently reflected. Again, this is explored further in the Social Inclusion chapter.

### **Who would make up the APG?**

The group should consist of a mix of people who have the authority to make high-level budgeting and strategic decisions as well as people who have a good understanding of the situation on the ground. It is also crucial that staff who attend come from both mental health and learning disability services. The group must have a full understanding of what services exist currently as well as where supply is not meeting demand for a type of service.

The group must be chaired by a senior commissioner who has a remit that covers both health and social care. If such a role does not exist, the group should be chaired jointly by two commissioners who between them cover both areas. Either way, the important thing is that it is not chaired by someone who only covers one side, as there would be a danger that the focus of the group would be skewed towards those types of services.

It is also very important that there is representation on the group from adults with autism and their family and carers. These people will have essential first-hand experience of accessing or trying to access services locally, and knowledge of what's working well and where the gaps in services lie.

The group must be made up of:

- commissioners for learning disability and mental health services
- managers of learning disability and mental health services
- representative(s) from the SAT
- representatives from the voluntary sector
- adults with autism and carers
- an appropriate representative(s) from children's services

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<sup>8</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

### **C) Is this model financially viable?**

Current service provision for adults with autism is inefficient and financially unsound. A failure to meet the needs of adults with autism results in multiple spending inefficiencies which waste huge amounts of public money.

The National Audit Office (NAO) investigated public spending into adults with autism<sup>9</sup> and found that failing to invest in autism provision is a huge false economy. The NAO found that if local services identified and supported just 4% of adults with HFA and AS the outlay would become cost neutral over time. Furthermore, they found that if they did the same for just 8% they could save the Government £67 million per year. The Liverpool Asperger Team, which is the longest-standing specialist Asperger service, reports identification rates of 14%. 4% therefore seems a very achievable figure for newly established SATs and APGs, thus achieving a cost-neutral level of service is an entirely realistic prospect in the medium term.

The NAO report details the main ways in which money is being wasted, particularly on those with HFA and AS:

#### Primary care and secondary mental health services

Given the right support many people with autism, particularly HFA and AS, will be able to live relatively independently in the community, requiring only 'low-level' services. Without this support, there is a far greater risk of social exclusion and therefore health problems, particularly mental ill health, developing.

As a result, people may only gain contact with services when their needs become acute, and they require more intensive, high level interventions and crisis management, such as psychiatric inpatient care. As the report states: *"Beside the negative impact of such crises on a person's life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day."* The services that many adults with autism need in order to be included in society, avoid isolation and decrease their chances of developing mental ill health, will usually be considerably cheaper to provide.

#### Out-of-area placements

Failure to plan and commission services for adults with autism at a local level means that many local authorities and PCTs place people in unnecessary out-of-area residential and inpatient services. The NAO found that 50% of authorities commissioned some services out of area, although over two-thirds were unable to provide figures for how much was spent on out-of-area residential placements<sup>10</sup>. On average, out-of-area placements cost the local authority more money, and will often be considerably more costly. Furthermore, there are obvious negative implications to placing adults with autism in a local authority away from where their friends and family live and the community that they are familiar with.

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<sup>9</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

<sup>10</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

While the NAS acknowledges that in some cases, people with especially complex needs will need specialist resources that it may not be reasonably expected for all local authorities to provide. However, the percentage of adults being placed out-of-area due to a lack of basic autism provision is too high, and is both unnecessarily expensive and a burden on individuals and their families.

### Unemployment

Only 15% of adults with autism are in full-time employment. As well as bringing psychological and social benefits to people with autism, a greater employment rate among this group would have obvious economic benefits for the Treasury through increased productivity and reduced benefit take-up.

## Implementing the strategy

### The reporting structure

Accountability must be established at all levels of National, Regional and Local Government in order for the strategy to be realised. The adult autism strategy must set out the chain of responsibility for implementation from the top down, such that it is easy to identify areas of responsibility if there is failure to comply at any level.

The Government has already committed to delivering establishing such a system, based upon learning from the Valuing People model:

*“Phil Hope will establish clear leadership for delivery of the strategy at national, regional and local level, learning from the model set out in the Valuing People Now strategy for people with learning disabilities.”<sup>11</sup>*

### Responsibilities at national level

#### *Leadership and capacity*

It is important that there is both appropriately senior leadership and sufficient capacity within the Department of Health (DH) to ensure that the adult autism strategy is delivered. Senior leadership is absolutely necessary for the strategy to receive the attention and priority it needs. Autism provision is already ‘playing catch-up’ with provision for other groups, which is the reason why the strategy is being introduced. If responsibility for delivering the strategy is not placed at a senior level there is a real danger that the strategy will fail to close that gap.

For these reasons we recommend that the model that has been introduced for learning disability, via Valuing People, must be mirrored as closely as possible in order for autism to be given the same degree of priority within DH. DH must therefore name a senior member of the civil service to be responsible for the implementation of the strategy. This role must be supported by sufficient staff with the capacity to do the work to ensure that the strategy is delivered.

#### *Cross-Departmental steering group*

Throughout the autism strategy consultation period DH chaired a cross-departmental strategy steering group, including civil servants from the Department of Work and Pensions, Department of Children Schools and Families. This has been a useful way of getting a degree of ‘buy-in’ from other Departments at an early stage, which is essential for a strategy that will cover areas that are not led by DH, such as employment and transport. We would strongly recommend that this steering group is retained and expanded to include senior civil servants from other Departments, including the Home Office, Department for Transport, Ministry of Justice and the Department of Communities and Local Government. It must meet regularly to monitor the implementation of the strategy.

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<sup>11</sup> Letter to all MPs from Phil Hope, Minister for Care Services, 19 February 2009

### *External Reference Group (ERG)*

DH have established an External Reference Group to help guarantee that the wide range of circumstances and experiences of those who are affected by or work in autism have been given full consideration in producing the adult autism strategy. The ERG has been an invaluable part of the process and will have contributed a great deal to the content and shape of the strategy.

The NAS would very much like to see the ERG retained in some capacity as the strategy is introduced and moves forwards. They would monitor the impact of the strategy in its maiden years and act as an advisory board if the strategy was not having the desired impact.

### Responsibilities at regional level

Diagram 1 sets out the reporting and responsibilities structure for regional and local levels, on page 28. For the purposes of clarity, this is explained in detail below:

#### *Deputy Regional Directors*

The **Deputy Regional Director** (DRD) must have ultimate accountability for the strategy within the Regional Government Office. This would make sure that responsibility for delivery regionally is held at a sufficiently senior level for the strategy to have the desired impact.

This would help to deliver the following existing Government commitment:

*“To support implementation of the strategy for adults across the whole autism spectrum, we will work through the Government Offices of the Regions to address what needs to be done in their regions to improve capacity and capability. This work will identify and address service improvements. It will include funding to support implementation of the strategy at a regional level...”<sup>12</sup>*

Mirroring the learning disability model, each of the country’s nine DRDs would have responsibility for delivering the strategy within their region, and additionally, one of these DRDs should have responsibility for promoting cross-regional learning and sharing of good practice on this issue.

#### *Regional Lead for Autism*

Working under the DRD, one member of staff will be given the role of **Regional Lead for Autism**. While it is important that accountability lies at the seniority level of the DRD, realistically this person will not have the capacity to actually do the required work. For this reason the Regional Lead will be a necessary part of ensuring progress is made through championing improvement at a regional level.

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<sup>12</sup> Letter to all MPs from Phil Hope, Minister for Care Services, 19 February 2009

## *Regional Autism Planning Group*

The Regional Lead will also share local good practice throughout their region. This would be achieved by establishing a **Regional Autism Planning Group**. This group would convene quarterly and be chaired by the Regional Lead for Autism. The local autism leads (see below), who would chair the Local Autism Planning Groups (see below), would attend this meeting, sharing ideas and good practice, trouble-shooting and commissioning at a regional level where appropriate.

This group is necessary for a number of reasons. Firstly, a large number of adults with autism are placed out-of-area, often within the region. Such placements must be scrutinised and addressed at a regional level. Sometimes, due to particularly rare and/or complex needs it will make sense for a service to be commissioned regionally rather than locally. In other instances out-of-area placements will be entirely unnecessary and a result of poor local planning. Again, these will best be scrutinised and managed at regional level.

Specialist autism provision is also relatively undeveloped and approaches to delivery, especially for those with more complex needs, can vary enormously from area to area. It is very useful to have a regular meeting in which good practice can be shared at a regional level to improve learning and consistency of delivery. Regional practice-sharing groups have been established in Greater Manchester and in the North East. They are well attended and seen as invaluable to those who do attend.

### Responsibilities at local level

A **lead member of staff** must be appointed to oversee and be responsible for the implementation of the strategy at a local level. The lead member of staff should be a sufficiently senior commissioner who has a remit that covers both health and social care, to help to ensure that services delivered by both local authorities and PCTs would be given equal priority.

The lead member of staff will also chair the **Local Autism Planning Group**. The group would consist of a mix of people who have the authority to make high-level budgeting and strategic decisions as well as people who have a good understanding of the situation on the ground. Staff would attend from both mental health and learning disability services in order to ensure a full understanding of what services exist currently as well as where supply is not meeting demand for a type of service. As explained previously<sup>13</sup>, the local APG would be responsible for developing appropriate services for adults with autism through effective local planning and commissioning.

The lead member of staff will report to the **Director of Adult Social Services (DASS)**, who will have ultimate responsibility for the implementation of the strategy at a local level. Guidance to the DASS in 2006 stated that they should make it clear which team or manager should be responsible for assessing and meeting the eligible needs of adults with autism<sup>14</sup>. Therefore it makes sense for this individual to have ultimate responsibility for the local delivery of the strategy.

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<sup>13</sup> A full explanation can be found in the SAT and APG chapter starting on page 10

<sup>14</sup> Department of Health. (2006) *Best practice guidance on the role of Director of Adult Social Services*. London: DH

A **Specialist Autism Team**<sup>15</sup> will be set up within each local authority / PCT partnership. At least one member of staff from the SAT must attend the Local APG meetings, to ensure good communication links between the two. The Specialist Autism Team would report to the lead member of staff for autism.

## **Inspections and evaluation**

Alongside this structure of accountability, inspection and evaluation will be necessary in order to examine how successfully the strategy is being implemented across the country. Well-intentioned Government strategies and policies have not always materialised into the desired action on the ground, so it is crucial that we establish a means by which to inspect implementation thoroughly and evaluate the success of the strategy.

### Care Quality Commission (CQC) inspectors must be autism-trained

New CQC registration requirements will focus on outcomes rather than standards, i.e. the inspection process will be based on the outcomes and experiences of service users. For these inspections to work for services providing support to adults with autism, CQC inspectors must have a good understanding of autism based upon mandatory training. For more detail on this training, see the Training chapter.

The Department of Health, working with CQC, must back up this training with new inspection guidelines which will support effective inspection of outcomes for adults with autism by CQC inspectors.

### National Indicators for autism

Public Service Agreement (PSA) 16 was introduced in order to increase the proportion of socially excluded adults in settled accommodation and in employment, education or training. The adult autism strategy will encompass similar aims for adults with autism, who are among the most socially excluded in the country.

PSA 16 specifically recognises adults with autism, including HFA and AS, as a group who are particularly vulnerable to social exclusion<sup>16</sup>. However, because there are no National Indicators relating to autism within PSA 16, the Agreement is not delivering for people with autism. Phil Hope has already committed to *“building on work to address the commitments in PSA 16 to support some of the most socially excluded groups of people into employment”*<sup>17</sup>. The Department of Health must work in partnership with the Department of Communities and Local Government and the Cabinet Office to develop National Indicators on local outcomes for adults with autism relating to PSA 16 and/or otherwise.

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<sup>15</sup> A full explanation of the role of the SAT can be found on page 10

<sup>16</sup> Under Priority Action 3 the Government identifies people with autism and Asperger Syndrome as part of the learning disability “at-risk” group: *“It will also be important for LDPBs [Learning Disability Partnership Boards] and social care services to consider the wider and more complex needs of those with autism and Asperger Syndrome.”*

<sup>17</sup> Letter to all MPs from Phil Hope, Minister for Care Services, 19 February 2009

## A thematic review

The Department of Health should also task CQC with carrying out a thematic review into implementation of the strategy on the first anniversary of its introduction, to ensure that progress is monitored from the start. If the strategy is thoroughly inspected in its maiden year this will provide further incentive for local authorities and PCTs to ensure that they are taking steps to deliver it from as soon as it is introduced. DH have commissioned similar reviews in the past, including on dementia, and learning disabilities and challenging behaviour. It is therefore not unreasonable for a similar review to be help into services for a group which DH have accepted are being failed by service delivery.

## **Statutory guidance**

### The need for statutory guidance

The Department of Health have committed to producing statutory guidance for local authorities, under Section 7 of the Local Authority Social Services Act 1970, and statutory guidance for PCTs, to accompany the strategy<sup>18</sup>. This is an extremely welcome commitment, and one that is crucial to the implementation of the strategy.

There are several elements of the strategy which will benefit greatly from being given a statutory footing. Legally binding duties will be much harder for a local body to ignore, and will ensure that elements of the strategy are given the level of priority that they require.

It is also very welcome that the guidance will make requirements of both local authorities and PCTs. Both local bodies are key to the success of the strategy and this is the best possible way to ensure that local buy-in from both health and social care is achieved.

In 2001, the Department of Health issued similar guidance to establish new duties on local authorities with regard to deafblind people<sup>19</sup>. The guidance placed legal duties on local authorities to carry out various measures, such as identification and data collection, assessments by appropriately trained professionals and provision of appropriate services.

As a result, this minority group, who had previously been almost universally ignored, began to see real improvements to the support they were receiving. Sense, the national deafblind charity, monitor the progress of implementation of the guidance each year. Although the results are still unsatisfactory, services for deafblind people were starting at a very base level. Sense found that in the five years between 2002 and 2007, the number of deafblind people identified by local authorities tripled<sup>20</sup>. Between 2003 and

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<sup>18</sup> Autism Bill, House of Commons Second Reading, 27 February 2009. Phil Hope MP: *“Once the strategy has been developed, we will be able to issue statutory guidance based on it, enabling every local authority to understand its obligations and the work that it must do to assess need, provide services, involve people in the development of their local strategies, and improve their work forces.”*

<sup>19</sup> The Department of Health issued *Social Care for Deafblind Children and Adults* (LAC 2001(8)) in March 2001 under the Section 7(1) of the Local Authority Social Services Act 1970

<sup>20</sup> Sense, Local authority survey report 2008, Jim Lewis

2006, the number of communicator guide<sup>21</sup> services being provided to deafblind adults increased by around 75%. The statutory guidance has clearly played an enormous part in improving outcomes for deafblind people since its introduction.

### Statutory guidance as proposed by the NAS

The NAS has drawn up an indicative version of what we would like to see included in the proposed guidance. We believe that it provides a robust legal structure by which services for adults with autism will be delivered and outcomes for adults with autism will be improved. Much of this proposed guidance merely reinforces existing duties local authorities and PCTs are subject to, and just acts to provide additional clarity as to how these duties impact upon adults with autism. For this reason, it is entirely reasonable to expect local authorities and PCTs to deliver these duties. The proposed guidance is as follows:

### **Proposed Statutory Guidance**

*Local authorities and PCTs, working in partnership, are required to:*

1. *ensure that one member of management staff of sufficient seniority has, within his/her responsibilities, overall responsibility for services for adults with autism, including the specific responsibilities to*
  - a. *secure the engagement in planning and commissioning services of*
    - i. *Local partner agencies*
    - ii. *commissioners*
    - iii. *service providers*
    - iv. *children's and adult services*
  - b. *involve people with autism and their carers in the planning of autism services;*
2. *ensure that there is sufficient appropriate local service provision to meet the needs of adults with autism.*
3. *have in place an agreed referral pathway for diagnosis and support for adults with a suspected ASD, including multi-agency assessments.*
4. *identify and maintain an accurate record of adults with autism in their local area;*
5. *ensure that the needs of adults with autism (including social care, health, housing, leisure and education needs) are properly addressed within local planning processes, including Joint Strategic Needs Assessments;*
6. *ensure that all assessments of adults with autism are carried out by staff with the appropriate skills, experience and qualifications to communicate with and assess the needs of an adult with autism;*

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<sup>21</sup> A communicator guide is a support worker specifically trained to help deafblind people to interact with the world around them through specialist communication and guiding, and is the most commonly required service among deafblind adults

7. *ensure all adults with autism receive services that are appropriate for their needs, recognising that adaptations may need to be made to mainstream services or those aimed primarily at people with a learning disability or mental ill health;*
8. *ensure that brokerage/advice services are available to all adults with autism, in particular ensuring that
  - a. *appropriate local post-diagnostic support is available to all adults with autism upon diagnosis*
  - b. *all adults with autism have appropriate support to purchase appropriate services through use of direct payments*
  - c. *all adults with autism who have needs that are ineligible for local authority funded support are helped to find appropriate support and services, and*
  - d. *all young people with autism are given appropriate support during transition from children's to adults' services, from age 14;**
9. *Develop and implement a training strategy to enable all staff to respond appropriately to the needs of people with autism.*

## **Funding**

As has been established throughout this response, there are numerous and significant cost savings to be made from providing a better service to adults with autism. The National Audit Office has established that millions of pounds of public money could be saved through better identification and provision for adults with AS and HFA<sup>22</sup>.

However, these savings will come about over the medium and long term. To establish new teams and new systems, to identify, diagnose and assess more adults and provide additional services and support to those adults, will all necessitate an initial outlay of funding.

For this strategy to really deliver better outcomes for adults with autism, the Government must acknowledge the significant spending increase that will be required. New funding, sufficient to carry out the actions set out in the strategy, including establishing Specialist Autism Teams in every local area, must be provided to local authorities and PCTs. Without this additional spending, local authorities and PCTs, many of whom are already financially-stretched, will struggle to implement the strategy and it will remain a well-intentioned but ultimately undeliverable policy document.

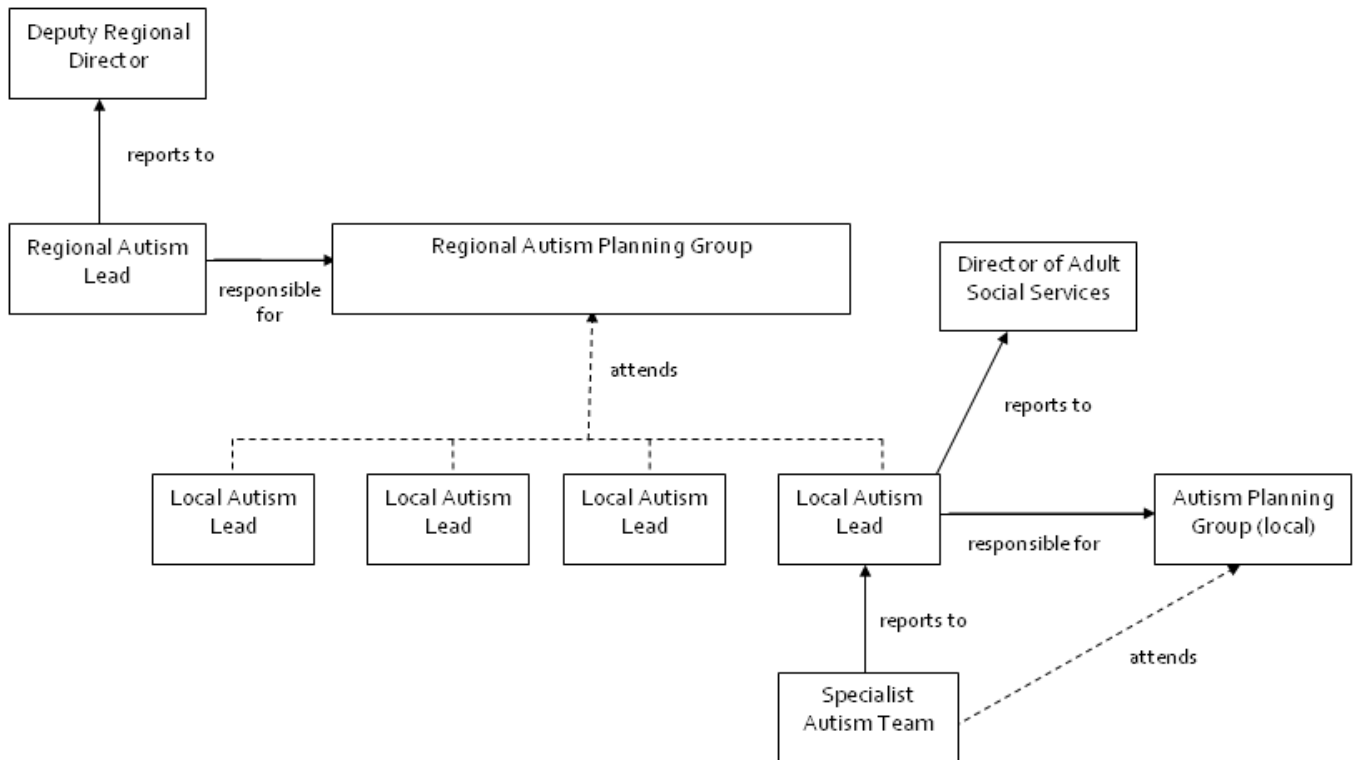
The Government has already committed to providing "*funding to support implementation of the strategy at a regional level*"<sup>23</sup>. The NAS would welcome a dialogue with DH to help determine the necessary levels of funding to implement the strategy.

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<sup>22</sup> These findings are explored in more detail on page 18

<sup>23</sup> Letter to all MPs from Phil Hope, Minister for Care Services, 19 February 2009

**Diagram 1: The reporting structure**



## Social inclusion

### Appropriate support and access to services

#### Local service structure

The current structure of social services is a major barrier for people with autism as they try to access support. Local authorities tend to provide services via specific teams which are categorised into client groups. Consequently, people with autism will usually come into contact with the learning disability team and/or the mental health team. However, as autism is a developmental disability and not a learning disability or a mental health problem, many people with autism, and particularly those with AS or HFA find themselves “falling through the gap” between learning disability teams and mental health services, as both fail to take responsibility for them.

*“ASDs cut across traditional service boundaries, so it is difficult to develop services in a way that allows for the sharing of expertise as well as funding.”* Local authority

This structural challenge has been recognised by the Department of Health, which has stated that *“the current position whereby some people with autism ‘fall through’ local services – in particular between mental health and learning disability – is unacceptable and contrary to the intention of government policy”*<sup>24</sup>. Yet this problem persists.

Indeed, our *I Exist* report revealed that over 60% of adults with AS or HFA say that they have experienced difficulties in accessing services and 52% of these were told that they do not fit easily into mental health or learning disability services<sup>25</sup>.

The issue of structural disadvantage does not only exist within local authorities – a clear support structure is absent among health services as well. When we asked PCTs whether they have a process to support adults with autism who are not eligible for either learning disability or mental health services, 55% who responded said they do not. This explains in part why many people with autism are unable to access health services<sup>26</sup>.

*“Bureaucracies can only cope with pigeon holes... ASD is not ‘core business’ for learning disability or mental health so will not be prioritised within their own ‘must dos’.”* Local authority

All the evidence points firmly towards the necessity to establish a specialist autism team (SAT) within every local authority / PCT boundary. Existing service structures are failing adults with autism, and there is a clear need for specialism at a local level, to build capacity within mainstream services through staff training and support, to assist with care assessments in complex cases and to provide and/or sign-post towards low-level autism-specific services for those who are falling through the gaps. The SAT would help existing services provide appropriate support to adults with autism, while simultaneously helping those adults to access those services.

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<sup>24</sup> Department of Health. (2006). *Better Services for people with an autistic spectrum disorder*. London DH. Page 7

<sup>25</sup> Rosenblatt, Mia. (2008) *I Exist*. The National Autistic Society

<sup>26</sup> Rosenblatt, Mia. (2008) *I Exist*. The National Autistic Society

Without a specialist team, it would be extremely difficult to build that capacity at a local level or to ensure sufficient autism expertise is available locally. Traditional service structures have consistently failed adults with autism, but the introduction of the SAT would enable those structures to work for this group across the country.

### Services for adults with autism and a learning disability

As outlined above, an incompatibility with existing service structures is a major barrier to support for those adults with HFA and AS. However, this is not to say that the picture is much rosier for those adults with autism who also have a learning disability, for whom this barrier should not exist. One recent study has shown that 38% of people with a learning disability also have autism<sup>27</sup> so to improve outcomes for all adults with autism we must ensure that the outcomes of adults with a learning disability significantly improve.

73% of local authorities now only support those with critical and substantial needs<sup>28</sup>, meaning that those adults with autism and a learning disability whose support needs are mild or moderate miss out on support in these authorities. Learning disability budgets in three quarters of councils were under pressure in 2005-6<sup>29</sup> and in 2006-7 were overspent by 2.7%<sup>30</sup>. For example, Hertfordshire Council have told us, via the Learning Disability Coalition of which we are a member, that despite a cash increase of 7.9% in their 2008/9 budget, including provision for a 4% real terms increase in funding, they are already projecting an overspend and expect overall a 5% increase in expenditure compared to 2007/08<sup>31</sup>.

The increase in numbers of people with learning disabilities has been estimated to be around 1% per annum. This would mean that the “true” number of people with learning disabilities in England would rise by 15% from 2001-2011 and 20% between 2001 and 2021<sup>32</sup>. Professor Eric Emerson has also recently estimated that there will be a growth in the number of adult social care users in a range of 2 - 5% (or 19 - 38% over a 6-8 year period) in two more recent local studies in Manchester<sup>33</sup> and Stockport<sup>34</sup>.

Clearly, with local authorities working with insufficient learning disability budgets and rising prevalence (and therefore demand) in an environment where they are already having to refuse services to all but those with the highest support needs, there is an urgent need to address these issues. The Green Paper on adult social care<sup>35</sup>, currently under consultation, must seek to improve this situation as a priority. At present, the Government adult social care policies set out in the Green Paper focus much more significantly on addressing the needs of the ageing population rather than on those with lifelong disabilities. This is unacceptable, in light of the above evidence, and the Government must ensure that the White Paper puts considerably more emphasis on

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<sup>27</sup> Bryson S. E. et al, Prevalence of autism among adolescents with intellectual disabilities, *Canadian Journal of Psychiatry*, 2008, Vol. 53(7), pp. 449-459

<sup>28</sup> CSCI (2008) *The State of Social Care in England 2006-7*

<sup>29</sup> Local Government Association (2006) *Social Services Finance 2005/06*. p.3

<sup>30</sup> Local Government Association (2008) *Report on Adults Social Services Expenditure 2007-8*

<sup>31</sup> Sarah Pickup, Director of Adult care Services Hertfordshire County Council

<sup>32</sup> Emerson & Hatton (2008) *People with Learning Disabilities in England*. Lancaster University

<sup>33</sup> Emerson, E (2007) *Estimating Future Need for Services for Adults with Learning Disabilities in Manchester*

<sup>34</sup> Emerson, E (2008) *Estimating Future Need for Services for Adults with Learning Disabilities in Stockport*

<sup>35</sup> *Shaping the future of Care Together* (2009): Department of Health

how outcomes for adults with a learning disability will be improved, and how the funding gap will be addressed for this group.

### Lead member of staff

Guidance to the Directors of Adult Social Services (DASS) in 2006 stated that the DASS should make it clear which team or manager should be responsible for assessing and meeting the eligible needs of a range of client groups, including those with autism<sup>36</sup>. This guidance was a significant development in that it specifically acknowledged that leadership was needed at a local level to ensure that the needs of people with autism were recognised. Yet our research showed that a lead on autism has been appointed in only 39% of local authorities<sup>37</sup>. Strong leadership and direction is clearly lacking locally.

Our research was backed by responses from local authorities to the 2007 CSCI self assessment survey<sup>38</sup>. Responding to a question about who was the lead individual or team for autism, a large number of local authorities asserted that the responsibility was split between mental health teams and learning disability teams.

*“Because of high IQ, I am not eligible and do not fit into any category for support. They do not recognise my disability and send me away. Even if I was eligible, there is no ASD support [here] for people like me.”* Adult with autism

The strategy must reinforce the DASS guidance, and explicitly require that an individual is named as responsible for delivering the strategy and complying with the accompanying statutory guidance. It is important that there is a member of staff who can be held accountable if progress in implementing the strategy is unsatisfactory, and also that there is an individual who will champion autism provision internally. The named lead must have their responsibility for delivering the strategy included in their job description.

It would be sensible and appropriate for the lead member to be the same person who chairs the Autism Planning Group. The two roles compliment each other, and delivery of the strategy is largely dependent on the success of the Autism Planning Group in ensuring service development, so the two responsibilities should be shared by the same staff member.

### Eligibility for services and preventative care

The 2008 CSCI review of eligibility criteria singled out people with autism as one of six groups of people whose needs were misunderstood by the current system, under Fair Access to Care Services (FACS)<sup>39</sup>.

People with autism have been marginalised under FACS for a number of reasons including: a lack of training of community care assessors; a dependence on families to

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<sup>36</sup> Department of Health. (2006) *Best practice guidance on the role of Director of Adult Social Services*. London: DH

<sup>37</sup> Rosenblatt, Mia. (2008) *I Exist: The message from adults with autism in England*. London: The National Autistic Society

<sup>38</sup> Copies of the responses from local authorities are available from CSCI

<sup>39</sup> Commission for Social Care Inspection, Review of FACS Eligibility Criteria. (2008)

provide support; a lack of preventative support in place for people with autism; a lack of signposting for those who did not qualify (rightly or wrongly) for support under FACS and a lack of prioritisation of social participation needs.

Using IQ as criteria for access to services was identified as a key problem by the CSCI review of eligibility criteria. The review noted that commonly where people were deemed ineligible because of IQ, they tended not to be referred to another social care team, even where they should have been eligible for support under FACS<sup>40</sup>.

The NAS welcomes the new consultation to review eligibility criteria and will be submitting a response. The guidance as reviewed must be absolutely clear that access to services on the basis of IQ is contrary to Government policy and unacceptable.

The tightening of eligibility of criteria across the country has also been a key issue for many adults with autism. Two-thirds of local authorities now only provide services to those whose needs are assessed as substantial or critical. CSCI's review of eligibility criteria noted that this has meant that as councils narrow their eligibility criteria, they also marginalise "low level" support services, as they assume that "low level" services are only required by those with low level support needs<sup>41</sup>. For people with autism, this means that councils do not prioritise a number of services that can offer a real lifeline such as befriending and social skills training, and which may prevent needs from increasing in the long-term. The way that eligibility criteria under FACS is applied incentivises councils to wait for people to get into crisis before offering support. Our research found that one-third of adults have developed mental ill health as a result of a lack of support<sup>42</sup>.

The Care and Support Green Paper<sup>43</sup>, currently under consultation, has listed prevention and early intervention as priority areas for improvement. However, the proposals in the Green Paper focus on care for those leaving hospital, investment in Telecare for older people and improving information. Crucially, it fails to propose prioritising low-level services that tackle social exclusion and prevent more significant further care needs or mental health problems developing. The kinds of services that are needed, but are all-too-often unavailable, are:

- social skills training
- travel and mobility training
- workplace skills training
- social support groups
- befriending and e-befriending schemes

Our research shows that the top three supports that parents of adults with autism believe would be of benefit to their son or daughter are befriending, social skills training and social groups<sup>44</sup>. The autism strategy must be clear about the need for all of the above services to be developed. The APG will have a large part to play in ensuring that

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<sup>40</sup> Commission for Social Care Inspection, Review of FACS Eligibility Criteria. (2008)

<sup>41</sup> Commission for Social Care Inspection, Review of FACS Eligibility Criteria. (2008)

<sup>42</sup> Rosenblatt, Mia. (2008) / *Exist: The National Autistic Society*

<sup>43</sup> Shaping the future of Care Together (2009): Department of Health

<sup>44</sup> Rosenblatt, Mia. (2008) / *Exist: The National Autistic Society*

those services are commissioned and developed, while the SAT will help to deliver some of those services and sign-post people to others.

### Ensuring quality of services and interventions

Although some research on interventions for children with autism has been carried out, the same cannot be said for adults. Relatively little research-based knowledge exists about what services and interventions are most successful for supporting adults with autism. We recommend that DH commissions new research to improve knowledge and understanding around effective intervention and therefore ensure that support for adults with autism achieves value for money.

To ensure that services are providing a high quality of appropriate support to adults with autism, DH must work with stakeholders to develop and fund an autism accreditation service. With new statutory guidance for local authorities and PCTs to compliment the strategy, and accreditation service could be used to work with local bodies to ensure that they are meeting those duties to an acceptable standard. Accreditation would also help adults with autism and their families to find services which are more likely to be able to meet their needs.

#### **Summary of recommendations:**

- A Specialist Autism Team must be established within every local authority / PCT boundary
- All local authority / PCT partnerships appoint a suitably senior member of management staff as responsible for implementing the autism strategy. This member of staff should also be the same as the chair of the Autism Planning Group, and should be a commissioner with responsibilities across health and social care
- The strategy, and the revised guidance on eligibility criteria, must make it clear that determining access to services on the basis of IQ is unacceptable
- The forthcoming White Paper on adult social care must address improving outcomes for adults with a learning disability as a priority, and in particular how the funding gap will be addressed for this group
- Preventative and 'low level' autism services must be prioritised by commissioners and budget holders
- DH must commission new research to improve knowledge and understanding around effective interventions for adults with autism
- DH must support the development of an autism accreditation service to work with local bodies and support them to meet agreed service standards.

## Assessments

### Appropriately trained professionals

*“The care coordinator is a social worker with the Community Mental Health Team who ‘feels out of her depth’ and ‘not trained to deal with this’.”* Parent of an adult with autism

All adults have the right to a community care assessment from their local authority, yet, despite this, the majority of adults with autism have not had one. Our research found that 42% of adults with autism say that they have had an assessment of their needs from their local authority since reaching adulthood and this figure drops to 35% among those people aged between 40 and 64<sup>45</sup>. Just 33% of adults say that they have received such an assessment in the last two years. This falls to just 25% among adults who have Asperger syndrome or high-functioning autism.

It is essential that whoever is conducting a FACS assessment has an understanding of the nature of the disability and that they know how to communicate with someone with autism in order to assess their needs properly and fairly. This will include consideration being given to an individual’s preferred method of communication (e.g. Makaton, Pecs), setting up meetings at times that suit them, providing access to an advocate and involving people who know the individual. It is important to understand the difficulty some people with autism have in defining what their needs and aspirations are; for example, some people with autism might not recognise or be able to explain their needs, or might answer a question in a way that they think the assessor wants them to. Others may be non-verbal or have limited capacity to communicate or take part in the process unless substantial adjustments are made.

Worryingly, our research found that local authorities do not think that care managers receive sufficient training in autism in their initial professional training (71%) and in their ongoing professional training (67%)<sup>46</sup>. Similarly, the NAO found that only 29% of local authorities’ training programmes for staff who carry out FACS assessments covered high-functioning autism<sup>47</sup>. Access to appropriate services is dependent upon assessors having a full understanding the needs of the individual. It is therefore unacceptable that so many local authorities are failing to provide the necessary training to the very people who act as the gateway to much-needed support.

*“My obvious verbal intelligence masks the level of my support needs. My mental health history biases ‘professionals’ against taking me seriously. The last support worker I had knew nothing about autism at all and could not understand the help I required.”* Adult with autism

The Department of Health has stated that *“proper individual assessments, based on eligibility criteria, as set down in ‘Fair Access to Care’ are the starting point for people getting the services they need.”* The guidance goes on to say that *“strong protocols ensure assessors are trained in ASD and they prevent people being delayed or denied access to services as a consequence of secondary testing (e.g. IQ testing).”*

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<sup>45</sup> Rosenblatt, Mia. (2008) *I Exist*: The National Autistic Society

<sup>46</sup> Rosenblatt, Mia. (2008) *I Exist*: The National Autistic Society

<sup>47</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

The Department of Health has also stated that services should be provided based on individual need, rather than assumptions about a condition or disability. It is essential that individuals are given an assessment by someone who understands autism. This must be ensured through appropriate training for those undertaking the assessments.

It is equally important that care assessments for adults with autism and a learning disability are carried out by autism-trained professionals as it is for those with AS and HFA. Adults with autism and a learning disability often do not have their autism taken into account and are therefore provided with inappropriate, often damaging, services. Many generic learning disability services and activities will not be suitable for adults with autism, including some group activities, for example. Residential placements where adults need to tolerate a high level of social interaction, or a noisy, chaotic environment may also cause great anxiety and stress. People with autism will often greatly benefit from routine and consistency in terms of activities and support staff, which is less likely to be an issue for adults with a learning disability who do not have autism. An assessment carried out by a trained assessor, based on an understanding of these types of issues, are much more likely to result in provision that meets the needs of the individual.

The role of the SAT is key to ensuring that care assessments are carried out fairly and appropriately. The SAT would train staff who carry out FACS assessments to be appropriately skilled to assess the needs of adults with autism based on a strong understanding about the condition and how it can effect day-to-day life. The SAT would also assist with assessments of individuals who have more complex needs. Where necessary, assessors will be able to call upon the expertise within the SAT, who will be able to make sure that adults with autism and particularly complex needs will be given appropriate assessments. In carrying out assessments jointly, assessors will also benefit from being able to learn through experience.

#### Outcome-focussed person-centred plan

FACS assessments must be complimented with a person-centred plan, carried out by an assessor who has been trained in autism. The plan must be outcome-focussed, based on the aspirations of the individual. This is covered in more detail in the *Choice and control* chapter.

#### Improving safeguarding through better support

Adults with autism can be extremely vulnerable both within a service setting and within the community. Because of their difficulties with social imagination, people with autism are often unable to properly interpret other people's intentions. They can take written and spoken words to be literal truth without discriminating or probing further and taken advantage of as a result.

People with autism can have profound problems in interpreting when someone is being unkind, leaving themselves open to abuse. The fear of displeasing people is also common among people with autism, meaning that often if someone with autism believes that someone is a friend then they may not seek to end the 'friendship' even where abuse is taking place or that they will go along with someone's wishes even when it is harmful to their wellbeing.

It should also be highlighted that adults with autism can be very isolated as a result of their condition, leaving them more open to abuse. Three-quarters of adults with autism either do not have any friends or find it hard or very hard to make friends<sup>48</sup> and 56% have been bullied or harassed as adults.

It is sometimes the case that the local authority itself has contributed in cases of abuse and neglect by failing to adequately fulfill its statutory obligations. The ombudsmen have been duly scathing in a number of cases relating to young people with autism whom local authorities have refused to adequately provide support for. These cases resulted in people being inappropriately locked up in secure psychiatric units and sedated without cause. In one case, someone was forgotten about in hospital for ten years and suffered abuse while there<sup>49</sup>.

These serious cases demonstrate the worst possible outcomes which may ultimately result from the underlying challenges facing adults with autism as they try to access services. Raising awareness of autism and increasing the number of professionals trained in autism would be particularly helpful in preventing inappropriate and harmful placements like the ones highlighted above.

Wider development of appropriate supports that could help adults with autism to become more independent and more included in the local community is also essential. This would include befriending, social skills training and social groups, as discussed above. These kinds of supports could help in tackling isolation and in the development of self-advocacy skills, both of which are central to preventing abuse.

#### **Summary of recommendations:**

- FACS assessments for adults with autism must be carried out by an appropriately autism-trained professional who has a good understanding of the nature of autism in order to assess their needs properly and fairly
- That strategy should make it clear that services should be provided on the basis of individual need, rather than assumptions about a condition or disability
- The Specialist Autism Team should support FACS assessors to carry out care assessments for individuals with more complex needs
- FACS assessments must be complimented by an outcome-focussed, person-centred plan

#### **Data collection, strategic planning and commissioning**

In order to plan and commission a sufficient amount of appropriate services for adults with autism at a local level, local authorities and PCTs must a) have a sound understanding of the prevalence of autism among their population, b) find out what services and support that population wants and needs, and c) use this information in

<sup>48</sup> Rosenblatt, Mia. (2008) *I Exist: The National Autistic Society*

<sup>49</sup> Mandelstam, M. (2009). *Community care and practice*. London: Jessica Kingsley Publishers

their strategic planning. We regularly find that all three of these necessary actions are neglected, and as a result service provision for adults with autism is extremely patchy, and generally poor, across the country.

Our research found that 67% of local authorities keep no record of how many adults with autism are in their area, and only 19% of local authorities say that they have a record that includes people with HFA and AS<sup>50</sup>. Those figures are even worse for PCTs – 77% keep no record of adults with autism, and only 9% have a record that includes people with AS and HFA. Similarly, the NAO found that only 18% of local authorities and PCTs could give precise numbers of adults with autism and a learning disability receiving services, and only 12% could do the same for high-functioning autism<sup>51</sup>. If we are to make real strides towards social inclusion for adults with autism, the importance of intelligent, proactive data collection, planning and commissioning cannot be overstated.

This message is also at the centre of existing Department of Health policy on autism: *“Policy requires public bodies to identify, assess and meet the needs of the local adult population and this should include people with an ASD. This overall responsibility falls to the Director of Adult Social Services and/or the Director of Public Health. They should ensure there is local data about local people, know what services are available to them and what the gaps are.”*<sup>52</sup>

### The need for an Autism Planning Group

These failures in data sharing and collection, strategic needs assessment and strategic planning will continue unless a specific group is set up to improve things. The National Autistic Society recommends that each local authority / PCT partnership sets up an Autism Planning Group, as set out on page 16.

The group would consist of a mix of people who have the authority to make high-level budgeting and strategic decisions as well as people who have a good understanding of the situation on the ground. It is also crucial that staff who attend come from both mental health and learning disability services in order to have a full understanding of what services exist currently as well as where supply is not meeting demand for a type of service.

It is essential that the group gets full ‘buy-in’ from both health and social care bodies and is not skewed in favour of one set of services over another. For this reason, the group must be chaired by a senior commissioner who has a remit that covers both health and social care. If such a role does not exist, the group should be chaired jointly by two commissioners who between them cover both areas.

Regionally, chairs of APGs would come together at regular intervals to share information and best practice from their areas, and plan and commission some services at a regional level where appropriate<sup>53</sup>.

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<sup>50</sup> Rosenblatt, Mia. (2008) *I Exist: The National Autistic Society*

<sup>51</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

<sup>52</sup> Department of Health. (2006). *Better Services for people with an autistic spectrum disorder*, page 8, London: DH

<sup>53</sup> For more on APGs see page 16

Through improved planning and commissioning, fewer adults with autism will be placed in costly out-of-area services, saving the local authority money. The NAO found that 50% of authorities commissioned some services out of area, although over two-thirds were unable to provide figures for how much was spent on out-of-area residential placements<sup>54</sup>. On average, out-of-area placements cost the local authority more money, and will often be considerably more costly. Furthermore, there are obvious negative implications to placing adults with autism in a local authority away from their friends and family live and the community that they are familiar with.

### Data collection and identification

The Government's Social Exclusion Taskforce identified the need for more reliable prevalence data and the adverse effect that the lack of such data leads to: *"We have insufficient epidemiological information reliably to estimate the prevalence of adult neuro-developmental disorders in the UK population... This is a major gap in the evidence needed to estimate the prevalence of chronic exclusion and the most effective responses to the needs of the people affected."*<sup>55</sup>

The Government has already begun the tendering process to carry out a national prevalence study, a development that we warmly welcome. It will be an extremely worthwhile exercise, not least for local bodies to use as a more reliable estimate for the number of adults with autism within their local population. If they have significantly fewer adults with autism on their records than the prevalence estimate suggests there should be, they will know that they need to be proactive in identifying greater numbers. We recognise however that the national study will not provide a definitive prevalence estimate, but rather an indication upon which to base further research. It is important that the Department of Health shares the learning from this study and uses it to develop tools to support local areas in applying or replicating the research.

Local data collection and identification must improve, firstly by improving information sharing between agencies, secondly by taking measures to identify those people who are not already known to services, and thirdly by having a shared database system that enables adults with autism to be distinctly recorded.

Phil Hope, Minister for Care Services, has previously committed to do the following:

*"We will address issues relating to the collection of data on adults with autism. As a first step we will engage with local communities, voluntary sector experts and carers to work out how to overcome existing problems with collecting information locally and we will develop proposals through the strategy to enable every locality to collect good data about the needs of people with autism living in the area."*<sup>56</sup>

This work should be led by the APG, and carried out as follows:

### *Information sharing*

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<sup>54</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

<sup>55</sup> Schneider, J. (2007). *Better outcomes for the most excluded*. The Institute of Mental Health, The University of Nottingham and Nottinghamshire Healthcare NHS Trust, Nottingham

<sup>56</sup> Letter to all MPs from Phil Hope, Minister for Care Services, 19 February 2009

The Government has committed to tasking the Public Health Observatory with looking into improving data collection and sharing on adults with learning disabilities among GPs. This is a very welcome measure, but must surely be extended to include information on adults with autism across the spectrum, not just those with a learning disability. On completion, the recommendations that develop from the investigation must be implemented swiftly.

However, GPs' records are just one source of data that must be utilised. The APG must look at data from special educational needs statements and as School Action Plus records. Where they exist, local disability databases and other relevant data sources must also be utilised.

### *Proactive data collection*

*"It's the quieter Aspies who miss out. There are loads of people who keep themselves to themselves so they never get identified for support, even though they could really use it."* An adult with Asperger syndrome

Sharing of information obtained through existing sources will only go so far. The APG must be proactive in finding other ways to identify people with autism who are not already known to services. Many adults with autism, and in particular those older adults who are less likely to have been diagnosed as children, would benefit from and be eligible for services, but will not have received an assessment of need as they have never been identified as having such needs.

One way to identify more of this group of adults is through GPs and other staff at doctors' surgeries, who will regularly come into contact with adults with undiagnosed autism. By sufficiently training these professionals to identify suspected autism and refer to their local SAT for diagnosis, identification rates could be greatly increased. Identification should also be increased by training frontline social workers, staff in job centres and Connexions to a similar level. Appropriate levels of training are explored in greater detail in the Training chapter.

Prisons should also be used to identify adults with autism. Approximately 7%<sup>57</sup> of the prison population has a learning disability. No data exists about the population of adults with autism in prisons, but it would be a reasonable assumption that screening prisons for adults with autism would be a cost-effective way of improving identification rates.

The Department of Health must work with best practice local authorities and trial local schemes in order to develop models to improve local authorities' data collection and record keeping of people with autism.

### *Improving data systems*

Local authorities have a duty<sup>58</sup> to maintain a list of people with disabilities in their area. The extent to which this duty is carried out varies between local authorities, some

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<sup>57</sup> University of Liverpool (Mottram 2007)

<sup>58</sup> National Assistance Act 1948, Section(4)(g) as amended by Sch. 23 Local Government Act 1972

keeping more complex databases than others. Most who keep such a database keep one out of functional necessity rather than because the duty exists. Databases tend to be passively kept – i.e. the local authority maintains the register rather than seeks out those who are eligible to go on it. Whilst this has obvious limitations, there is a value in maintaining voluntary registers as it enables those who are not in receipt of services to put themselves forward to be counted.

The strategy must clarify the duty on local authorities to maintain databases to ensure that people can be identified by *type* of disability, including autism. This way local authorities will have much better information on the local autism population which can help to inform their local planning and commissioning strategies, as below.

### Strategic planning and commissioning

Joint Strategic Needs Assessments (JSNAs) are the key tool used by local authorities and PCTs to plan and commission services for the local population, and are intended to be inclusive of all groups. However, research from the National Audit Office found that only 21% of JSNAs included specific reference of autism. 86% of local authorities told the NAS that with better information on adults with autism in their area they could improve long-term planning, which strongly indicates that the current shortage of information is having a negative impact on the development of services for adults with autism.

The Government's good practice guidance on JSNAs<sup>59</sup> states that:

*“Specifically, JSNA is a tool to identify groups where needs are not being met and that are experiencing poor outcomes”*

and also:

*“Ensuring the engagement of particularly vulnerable and hard to reach groups, those with complex medical and social care needs and those experiencing exclusion will be one of the significant challenges of JSNA. Their involvement is important, since they are more likely to suffer from poor health, wellbeing and inequalities, and their engagement with JSNA will best shape services to meet their needs.”*

Adults with autism, who seem to fit exactly within the criteria that local authorities and PCTs are supposed to make particular effort to include, are being routinely ignored by the JSNA process. It is clear that this must be addressed as a priority, or else people with autism will remain an after-thought rather than an integral part of joined up service planning and provision.

The evidence demonstrates that without a specific instruction to do so, the majority of local authorities and PCT partnerships are not including adults with autism in JSNAs, and are therefore failing to plan appropriate services. It is clear that the needs of adults with autism are overlooked by many local bodies, so it is crucial that the statutory guidance that will accompany the autism strategy commands JSNAs to include the

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<sup>59</sup> DH in partnership with DCLG (2007): Guidance on Joint Strategic Needs Assessments

needs of adults with autism. The APG's work must link closely with the JSNA to inform of the needs of the local autism population.

The Government issued a core dataset to help JSNAs estimate the prevalence of people with various needs within their locality. However, it makes no reference to any data which includes mention of autism. POPPI, which estimates need amongst the older population, is referenced. But its equivalent for disability, PANSI, which includes a prevalence estimate for autism, is not included. Until the Government's own prevalence study is completed, the core dataset must be amended to include PANSI, and once the prevalence study has been finished the population estimates obtained must also be included within the core dataset.

The Department of Health must also follow through on their commitment to publish *"good practice guidance, which will set out what a good JSNA looks like, to help assessors identify the needs of people, like those with autism, who may be at risk of falling through the net"*.<sup>60</sup> This guidance, which has been promised for this year, must explicitly and thoroughly address the issue of autism and how best to ensure that the needs of adults with autism are reflected in the JSNA process.

The Government must also follow through with the commitment to produce world class guidance for commissioners to improve strategic commissioning for adults with autism.

#### **Summary of recommendations:**

- The Department of Health must continue with plans to conduct a comprehensive national prevalence study, and must consult with stakeholders, including the NAS as part of the tendering process
- An Autism Planning Group must be set up, consisting of learning disability and mental health commissioners and managers, representative(s) from the SAT, representatives from the voluntary sector, adults with autism and carers and a representative from children's services. It must be chaired by a senior commissioner who covers both mental health and learning disability services.
- The Autism Planning Group must ensure that existing sources of information are brought together, including SEN data, GP records and local disability databases to gain a better understanding of the local autism population
- The Autism Planning Group must take proactive steps to identify adults with autism currently unknown to services, with support from the Government Offices and the Department of Health
- The Department of Health must work with best practice local authorities and trial local schemes in order to develop models to improve local authorities' data collection and record keeping of people with autism

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<sup>60</sup> Letter to all MPs from Phil Hope, Minister for Care Services, 19 February 2009

- The chairs from local Autism Planning Groups must convene at a regional level to share information and best practice, and to commission strategically at a regional level where appropriate
- Local authorities must carry out their existing duty to maintain disability databases and must ensure that these databases can identify people by type of disability, including autism
- The strategy must put a specific statutory requirement on local authority / PCT partnerships to include the needs of adults with autism in their Joint Strategic Needs Assessments
- The Public Health Observatory's investigation into improving data collection and sharing on adults with learning disabilities among GPs must be extended to include information on adults with autism across the spectrum, not just those with a learning disability
- Screening tools should be used in prisons to identify adults with autism
- The PANSI data-source and outcomes of the national prevalence research must be added to the JSNA core dataset
- The good practice guidance on JSNAs, due to be published this year, must explicitly and thoroughly address the issue of autism and how best to ensure that the needs of adults with autism are reflected in the JSNA process
- The Government must follow through with the commitment to produce world class guidance to improve strategic commissioning for adults with autism.

## **Housing and support**

According to research from the NAO, approximately 65% of local authorities had difficulty finding appropriate residential placements in their area<sup>61</sup>. This has led to a significant number of adults with autism either being placed in inappropriate accommodation or placed out of area, while many still live with and rely upon their parents. Our research found that 41% of adults with autism live with their parents, rising to 50% for adults with autism and a learning disability<sup>62</sup>. The APG, by gaining a much better understanding of local need in relation to autism than currently exists in most localities and by ensuring inclusion of the needs of adults with autism within JSNAs (as discussed above), must work to improve this situation.

Adults with autism face a number of issues which have an effect on where is and is not appropriate for them to live. For example, adults with autism may struggle in a social housing or supported living arrangement with noisy or chaotic environments, or which necessitates a large degree of social interaction. Houses near busy roads or on particularly in areas with high crime rates may be inappropriate as some adults with autism are often particularly vulnerable and have a limited sense of danger. Location

<sup>61</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

<sup>62</sup> Rosenblatt, Mia. (2008) *I Exist*: The National Autistic Society

can also be an issue if adults are placed far from their previous home as they may struggle to adapt to a new community or have difficulty without their family and support network in close proximity.

In developing their housing strategies, local authorities must take into account the various needs of the adults with autism in their area. Local authorities must ensure that the range of needs of adults with an ASD and the adaptations that may need to be made are properly considered. Environmental and sensory issues are particularly important in an adult with autism's home, so must be given full consideration when housing plans are drawn up.

DH is currently working with the DCLG to try to ensure that mainstream housing policies are inclusive of people with learning disabilities. This work must be expanded to include all adults with autism, including those who do not have an accompanying learning disability.

Housing planning must also take into account the specific support that someone with autism might need to live in a supported living arrangement, to ensure that this option is available for those who would prefer supported living to residential care. This support must be suitable for adults with autism. Local authorities should also review the support offered by their Supporting People services with a view to ensuring that appropriate housing support is available for adults with autism.

Local authorities may struggle to fully understand the needs of adults with autism when they develop their housing plans. For this reason they must consult with adults with autism and their families in developing these plans. The DH must also work with the DCLG to develop guidance on the accessibility requirements of housing for adults with autism.

Housing needs must also be included in transition plans for young people with autism. Planning must help to ensure that individuals have a genuine choice between supported living, residential and private renting and shared ownership schemes.

**Summary of recommendations:**

- The Autism Planning Group must ensure that suitable residential or supported living arrangements are available locally for adults with autism
- Commissioners must be autism-trained to ensure that they commission appropriate support for adults with autism
- The Department of Health must extend its work with the Department of Communities and Local Government to ensure that mainstream housing policies are inclusive of all adults with autism, including those who do not have an accompanying learning disability
- Local authorities must give the specific needs of adults with autism full consideration when developing housing plans, including environmental and sensory issues, through consultation with adults with autism and their families

- 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 autism
- The Department of Health must work with the Department of Communities and Local Government to develop guidance on the accessibility requirements of housing for adults with autism
- Housing and support needs must also be included in transition plans for young people with autism. Planning must help to ensure that individuals have a genuine choice between supported living, residential and private renting and shared ownership schemes upon reaching adulthood.

## Transport

### Access to public transport

Many adults with autism find public transport inaccessible and difficult to use. The environment can be stressful because of sensory issues, crowded spaces or other reasons. Delays to services can cause anxiety and panic, and many will need support to plan and undertake a journey.

For many, being able to use public transport can be the difference between isolation and having a social life within their community. Accessible public transport can therefore play a huge part in combating social exclusion in adults with autism.

It is very important that transport needs are given full consideration in an individual's person-centred plan and in the care assessment process more generally. An adult with autism may be *physically* able to travel alone, but may need a lot of support to actually undertake that journey, and that support must be reflected in their support package. Support, for example might include a travel training course to use public transport independently and safely or a companion to accompany them on journeys. It is important that when planning and commissioning local services, the APG ensures that travel training is available in the area. This is the kind of low-level service that the SAT could provide.

Other adjustments, such as improved audio and visual cues on trains and buses will also help many adults with autism to travel independently and reduce potential for stressful situations to arise. For this reason, adults with autism must be involved in local decision-making processes about transport. When a new service is being planned or updated, adults with autism must be included in the process to ensure that those minor adjustments that could make a big difference to their ability to travel independently are acknowledged and implemented. To the same end, the Department for Transport, working with the Department of Health, should produce guidance on making transport accessible for people with autism.

We have also been made aware of several cases in which adults with autism have attempted to get concessionary bus passes on account of their disability, but have been despite providing proof of diagnosis. Guidance on eligibility for the pass states that it should be offered to those whose disability is permanent and *“should have a substantial*

*effect on a person's ability to carry out normal day-to-day activities*<sup>63</sup>. People with autism would usually be deemed eligible on this basis, and the Department of Transport should clarify policy on entitlement to the passes for people with autism.

Some adults with autism, particularly those with complex needs, need a companion in order to safely use a bus. However, the concessionary bus passes that these individuals are given only include a pass for the companion at the discretion of the local authority, and most local authorities do not issue these passes. This means that, essentially, these adults are not getting free travel at all – they need a companion to travel, and have to pay for that companion. Given that these people are likely to be amongst the least well off in the country, it is unacceptable that they are having to pay to travel. The national concessionary bus pass scheme must be amended such that free companion bus passes must be issued to adults with autism who need a companion in order to use a bus safely.

### Blue Badges

Many adults with autism, or parents of an adult with autism, would greatly benefit from having a Blue Badge. Some people with autism will have little or no sense of danger, especially when distracted by something relating to one of their interests or when affected by an irrational fear. Others may not always understand traffic rules or have sensory difficulties which can make traveling by public transport difficult. Other challenging behaviour can include:

- refusing to walk or sitting down in the street and not moving
- ignoring instructions near busy roads/in dangerous situations
- walking extremely slowly and cannot be persuaded to speed up

A Blue Badge can enable people with autism to travel in a safe manner and avoid the stress and anxiety that traveling by public transport can cause or the disruption to routine that can come from having to search for a parking space.

*"I have a daughter with Asperger syndrome and parking some distance from our destination causes the following problems: my daughter gets stressed because she is unable to 'predict' where we will be parking. She is very unpredictable in traffic and is not able to judge the speed at which cars are travelling towards us when crossing a road. She will often either leap out at the wrong time or stand frozen unable to proceed. Being able to park close to a destination would solve all of the above problems."*

Parent of child with autism

### *Medical Assessment*

We welcome commitments to make the assessment process for blue badges more consistent. However, we feel that it is important that clear guidance is issued to those medical practitioners carrying out assessments for Blue Badge. The National Audit Office found that 80% of doctors surveyed about their experiences of autism felt that they needed more training in the disability. We would be worried that those doctors

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<sup>63</sup> Guidance to local authorities on assessing eligibility of disabled people in England for concessionary bus travel, Department of Transport, February 2008.

carrying out medical assessments for Blue Badge might not have sufficient knowledge of autism.

Currently, there are considerable variations between local authorities with regards to the eligibility of people with autism for Blue Badge. Clearer guidance, specifically including autism, would address this. In the current Local Authority Guidance it states:

*“Medical conditions such as ... autism ... are not in themselves a qualification for a badge. People with these conditions may be eligible for a badge, but only if they are in receipt of HMRCDLA on account of their condition or are unable to walk or have very considerable difficulty in walking, in addition to their condition.”*

Many local authorities understand this to mean that people with autism are not eligible for Blue Badge. We recommend that along with the inclusion in Local Authority Guidance of guidance on how people with autism may require a Blue Badge (irrespective of any DLA claims) the above language should also be removed. As outlined above, aside from the ability to walk there are many considerable challenges faced by adults with autism with regard to transport in general, and car travel specifically, and these should be fully reflected in decision-making about Blue Badge eligibility.

#### *Blue Badge and Disability Living Allowance*

Although we recognise that the Department for Work and Pensions is working to improve decision making in this area, currently many people with autism and carers of people with autism are turned down for the Higher Rate Mobility Component of Disability Living Allowance (HRMCDLA).

In our experience it is not unusual for individuals not to receive the mobility component at all, despite receiving higher or middle rate care component. This may reflect a lack of appreciation of the way in which an individual’s support need affects their ability to travel. The NAS are therefore concerned about moves to more closely align eligibility for Blue Badge with HRMCDLA.

#### **Summary of recommendations:**

- The specific transport needs of adults with autism must be given full consideration in FACS assessments and person-centre plans
- The Autism Planning Group must ensure that travel training for adults with autism is available locally
- Adults with autism must be involved in local decision-making processes about transport
- The Department for Transport, working with the Department of Health, should produce guidance on making transport accessible for people with autism
- Department of Transport should make it clear to the bodies that issue these passes that adults with autism are entitled to disability bus concessions

- The national concessionary bus pass scheme must be amended such that free companion bus passes must be issued to adults with autism who need a companion in order to use a bus safely
- Blue Badge eligibility for people with autism and their families must be determined according to need, not by medical definition or ability to walk
- Clear guidance about the transport needs of people with autism must be issued to medical practitioners carrying out Blue Badge assessments

## Health

### Diagnosis and post-diagnostic support

#### The lack of diagnostic services

There is an alarming lack of diagnostic services for adults across the country and for many adults with autism, accessing a diagnostic service can seem impossible. Our research found that 48% of PCTs do not have an autism specialist diagnostic service or even an identified person who can undertake assessment within their locality<sup>64</sup>. Those PCTs that told us that they can undertake assessments within their boundary often offer a limited service, not of a specialist nature. Very few PCTs could tell us how many adults with autism in their area had received a diagnosis that year.

It has also been found that in England there are only 14 NHS teams or individuals who actually diagnose autism in adults<sup>65</sup>.

Although eligibility for social care and support should always be based on the needs of the individual and not diagnosis, we have found that this is not always the case. In fact, 54% of local authorities believe that adults with autism who have a diagnosis are more likely to receive support than those without one. Therefore it can be concluded that a lack of diagnostic services is a major factor in adults with autism failing to receive the support that they need.

*“It has been horrendous. I tried everyone – education, psychology, social services, adult services, doctor. No diagnosis – no help. How do I get a diagnosis? What support do I get if there is no diagnosis? Will it take attempted suicide before anyone acts?”*

Adult with autism

A failure to get a diagnosis can also have a major impact on an individual’s wellbeing and mental health. Adults with autism can struggle for years in employment and social settings, aware that they are ‘different’, but unaware that they have a recognised condition. Diagnosis can help individuals to make sense of their lives. Moreover, low levels of support can often make a huge difference to the life of an adult with autism, but without a diagnosis many people will not know that they have a condition for which support may be available, and will feel that they have no starting point from which to access support.

Awareness of autism is increasing, but for many adults with autism there was little knowledge of the condition when they were children. In fact, Asperger syndrome has only been part of diagnostic manuals in England since 1994. As a result many adults have been misdiagnosed with mental health conditions such as schizophrenia. Others will have had their learning disability recognised, but their autism remains undiagnosed. This may have led to inappropriate service provision or medication, and autism diagnostic services create an opportunity to rectify inappropriate, and thereby inefficient, interventions for this group.

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<sup>64</sup> Rosenblatt, Mia. (2008) *I Exist: The National Autistic Society*

<sup>65</sup> Autism Services Directory, National Autistic Society

## The need for local diagnosis

The Royal College of Psychiatrists have recommended that “*commissioners should ensure that there is access to local, basic diagnostic expertise that would allow the firm diagnosis of autistic spectrum disorders in clear cut cases.*”<sup>66</sup> The NAS strongly supports this recommendation. The Government's autism strategy must ensure that this local diagnostic expertise is always available such that adults with autism can access the diagnostic service that will so often be the starting point to accessing support.

Because of the scarcity of diagnostic services, when people do manage to get a referral for diagnosis it will more often than not be for a service that is out of area and subject to a lengthy waiting list. The introduction of the SAT will change this, acting as the local base for adults with suspected autism to be referred for diagnosis. The SAT will include at least one member of staff – a clinical psychologist/psychiatrist or equivalent – who has the training and expertise to diagnose, so will be able to diagnose in all but the most complex of cases.

Diagnosis must be a multi-disciplinary process. The psychologist/psychiatrist needs to be able to call upon other areas of expertise from within the SAT to support the diagnosis process, including a social worker, a speech and language therapist, an occupational therapist, a physiotherapist or a psychiatric nurse. If these professionals are not available from within the SAT, they would be called in from external services.

## Regional specialist services

In the same report mentioned above, the Royal College of Psychiatrists also recommend the following: “*They [commissioners] should also ensure access to a second level of diagnostic expertise for those individuals where there is diagnostic uncertainty.*” Again, we agree with this recommendation<sup>67</sup>.

It is important that regional specialist services for autism at Strategic Health Authority (SHA) level are established throughout the country, as set out by the Specialised Services National Definitions Set for Mental Health Services.

As explained in the Definitions Set, a small number of people with autism have sufficiently complex needs that the SAT may struggle to diagnose effectively. These individuals will therefore be referred to regional specialised services. As set on in the Definitions Set, the roles and responsibilities of this specialist service would include:

- multi-disciplinary diagnosis, assessment and management advice for complex individuals where there is ongoing local diagnostic uncertainty
- advice and support to families and carers
- consultation and supervision for health and social care professionals
- in-patient facilities for ASD non-forensic patients, providing co-ordination and gate-keeping

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<sup>66</sup> The Royal College of Psychiatrists (April 2006), *Psychiatric Services for Adolescents and Adults with Asperger Syndrome and Other Autistic-Spectrum Disorders*

<sup>67</sup> The Royal College of Psychiatrists (April 2006), *Psychiatric Services for Adolescents and Adults with Asperger Syndrome and Other Autistic-Spectrum Disorders*

- ensuring appropriate referral and facilitating discharge back to the local service.

### Lack of diagnosticians requires investment

The above model will require Government investment in training more professionals with the skills to diagnose autism in adults. Currently, there are very few professionals with this expertise. If the Government is serious about improving diagnosis rates to provide support to more adults with autism, it must invest in a training programme to increase capacity in this discipline.

### NICE guidelines

The National Institute for Health and Clinical Excellence (NICE) has committed to developing a clinical guideline for the initial recognition, referral and diagnosis of autism in children and adolescents. This commitment was in response to huge variations in diagnostic services across the country, including waiting times and diagnostic practice. It was acknowledged that these variations were having a detrimental effect on children and families' ability to access appropriate interventions and support and as such a national clinical guideline must be developed.

Regrettably, despite access to diagnostic services being even more difficult during adulthood than they are for children, the NICE guidelines will not cover diagnosis for adults. Almost three quarters of PCTs told us that they believe that there are constraints to providing access to diagnosis for adults with autism<sup>68</sup>. Excluding adults from these guidelines seems a puzzling omission. We would strongly recommend that the NICE guidelines are extended to include recognition and diagnosis in adults.

### Post-diagnostic support

While for some it may simply be a relief to have confirmation of a long-suspected condition, for many receiving a diagnosis of autism can be a traumatic and devastating experience. Without post-diagnostic support, adults with autism can be left isolated, confused and vulnerable.

Because the majority of PCTs do not offer a diagnostic service, most adults with autism who get a diagnosis end up receiving it out of area. Consequently, the individual will often return to their local authority with a diagnosis of autism but will find it impossible to access the post-diagnostic support they require as it simply does not exist in their home authority.

Even when an individual does receive diagnosis in-area, a poor quality diagnosis which does not take into account their wider needs coupled with a lack of post-diagnostic support, can mean that they are equally isolated and unsupported after receiving diagnosis.

Through the SAT, people will receive their diagnosis locally and will then be in a position to receive appropriate post-diagnostic support from the very same service. As part of a post-diagnostic service, the SAT should offer:

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<sup>68</sup> Rosenblatt, Mia. (2008) / *Exist: The National Autistic Society*

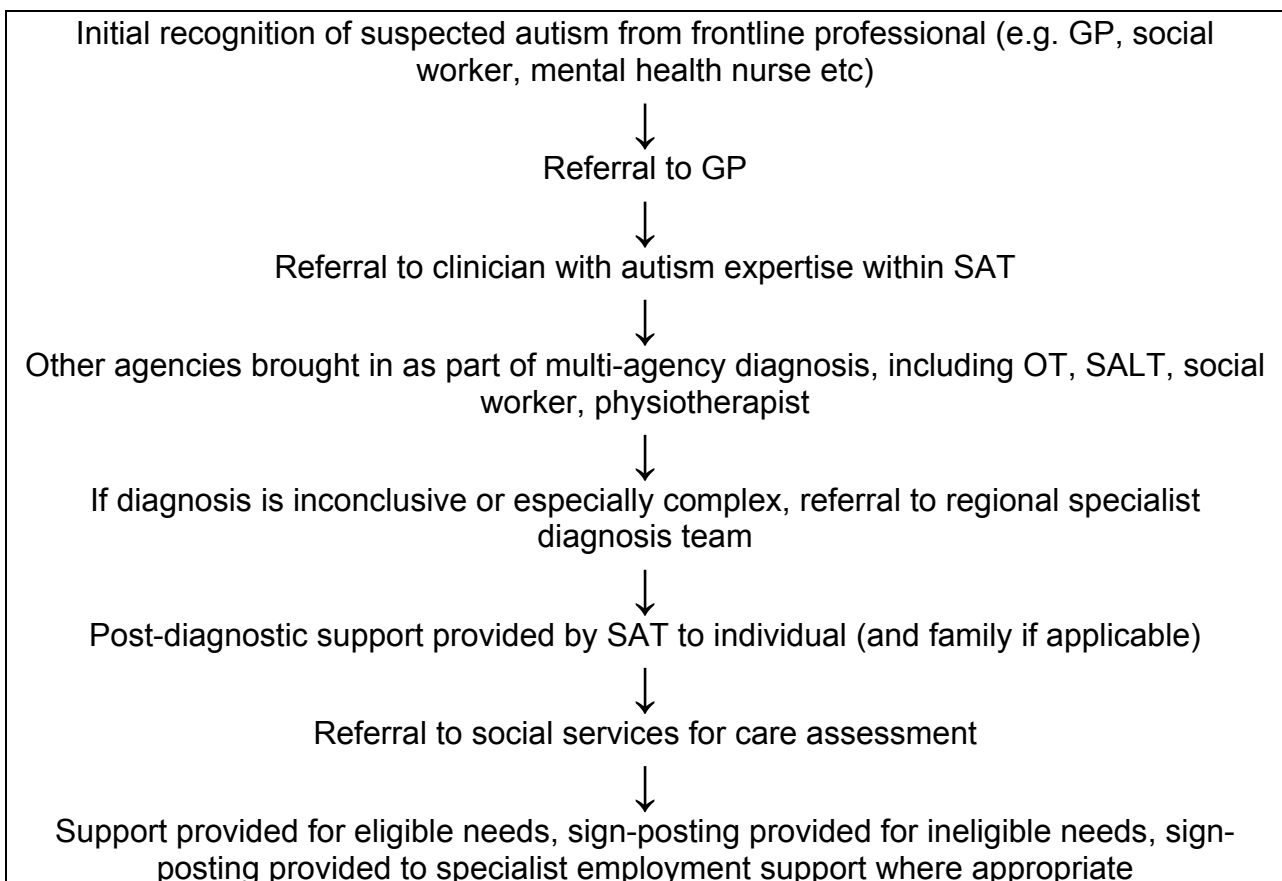
- counselling to help individuals come to terms with the diagnosis
- help to get in touch with social services to get an assessment for support
- training to help the individual and their family to understand the condition and what it means for their life
- information and advice about autism, including contact details for support groups and appropriate helpline services
- signposting towards specialist employment support where appropriate

Referral pathways for diagnosis and support

Frontline health and social care staff have a crucial role in identifying and referring adults with suspected autism for diagnosis. GPs, in particular, will be key to identifying those adults who are undiagnosed and not known to services.

SATs must develop comprehensive, transparent referral pathways for diagnosis and support. The individual must be able to be clear about the process by which they can get diagnosed, and which professionals they will need to see and in which order.

Pathways can be worked out at a local level, but a suggested model is below:



Sufficient training must be given to all healthcare professionals in order to implement an effective referral pathway. This training will be delivered by the SAT. Details about what training levels should be considered sufficient can be found in the Training chapter of this response.

### **Summary of recommendations:**

- DH must ensure that adult diagnostic services are available at a local level
- The SAT must include at least one member of staff (a clinical psychologist/psychiatrist or equivalent) who is qualified to diagnose adults with autism
- Diagnosis must be a multi-disciplinary process, involving a range of different professionals
- Regional specialist services for autism must be established at Strategic Health Authority level
- The Government must invest in a training programme to increase the number of clinicians who are qualified to diagnose autism
- The remit of the NICE guidance on diagnosing autism in children must be extended to include diagnosis of adults
- Comprehensive post-diagnostic support must be provided by the SAT as part of the diagnostic process
- SATs must develop comprehensive, transparent referral pathways for diagnosis and support
- Sufficient training must be given to all frontline healthcare professionals such that they are able to recognise signs of autism as part of the referral pathway

### **Access to primary healthcare**

#### Health inequalities

In 2006, The Disability Rights Commission conducted an enquiry into the health inequalities experienced by people with learning disabilities and mental ill health. The scope of the study included *“people with conditions which are long term and have a significant adverse effect on the person concerned. This would include ... people with autistic spectrum disorders”*<sup>69</sup>. The DRC investigation found this group to be significantly more at risk of developing major health problems.

This year, an Independent Inquiry found that people with learning disabilities routinely experienced health inequalities within the NHS. The Government has since announced that £100 will be paid as incentives to GPs carrying out annual health checks on adults with learning disabilities. This is a welcome development, and will benefit the many people with autism who have an accompanying learning disability. However, adults with high-functioning autism and Asperger syndrome are equally likely to be isolated, lacking

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<sup>69</sup> *Equal Treatment: Closing the Gap A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*, Disability Rights Commission

in support and living unhealthy lifestyles. The annual health-checks initiative must be extended to include adults with autism who do not have a learning disability, into to help combat health inequalities within this group.

### Better healthcare settings

*"Waiting rooms are a nightmare. My current GP practice has a big open plan waiting room containing a TV which plays health videos and flashing red signs with information about opening hours etc in various "strategic" positions. I need a quiet waiting room and soft lighting. Why must the NHS always use fluorescent lights?"* An adult with Asperger syndrome

It is crucial that healthcare settings are accessible to adults with autism. If a hospital or doctor's surgery is inaccessible it becomes very hard for adults with autism to access the most basic of healthcare. Adults with autism may refuse to visit these places or if they do visit them, may become agitated while there, making communication and cooperation much more difficult.

There are some simple reasonable adjustments that can be made to healthcare settings that can make a huge difference to the experience of people with autism. Many people with autism have additional sensory problems, and can be especially sensitive to light and sound. People with autism can also struggle in crowded or busy spaces, for instance. The Department of Health should produce guidance for healthcare settings, setting out the kinds of adjustment that they should make to their waiting rooms, wards and surgeries to ensure that adults with autism are not adversely affected. The strategy should also emphasise to hospitals, mental health settings and doctor's surgeries that in drawing up their Disability Equality Schemes under the Disability Equality Duty, they should ensure that adults with autism are consulted about how to make the setting accessible to them.

Guidance from the Department of Health should also include information about how to ensure that reasonable adjustments are made for people with autism such that they are not subject to indirect discrimination. Adjustments might include allowing an adult with autism to bring someone to accompany them as a 'translator' and producing information such as prescription instructions in plain English or easy read.

### Improving mental health services for adults with autism

People with autism will often have comorbid mental health conditions unrelated to their autism. Our research found that 33% of adults have developed additional mental health needs because of a lack of support<sup>70</sup>. Research from the Office of National Statistics (and others) has found mental health conditions to be many times more likely to be experienced by children with autism<sup>71</sup>. Although similar research has not been carried out for adults but it is safe to assume that prevalence among this group is similarly high.

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<sup>70</sup> Rosenblatt, Mia. (2008) / *Exist: The National Autistic Society*

<sup>71</sup> This research is explored in greater detail in the Training chapter

These comorbid conditions will commonly be things such as anxiety and depression, but can also be serious psychotic illnesses or severe behavioural problems.

Improving Access to Psychological Therapies (IAPT) is DH's programme to support PCTs to implement NICE guidelines for people suffering from depression or anxiety disorders. Unfortunately, this programme is not accessible to adults with autism. At present, training for staff delivering this programme does not cover recognition of autism-specific difficulties, i.e. the different impact such mental health problems may have upon a person with autism and adjustments that would need to be made to delivering therapies.

Mainstream therapeutic approaches will often involve doing things that an adult with autism may find impossible, such as putting yourself in someone else's shoes or imagining hypothetical situations. For therapeutic methods to work successfully for adults with autism, modifications must be made to tailor the approach to the individual. This tailored approach will not be delivered unless those professionals administering IAPT are specifically trained to make the necessary adjustments for patients with autism. Considering the prevalence of comorbid mental health problems, particularly anxiety and depression, among adults with autism, this must surely be recognised as a priority in the strategy.

It is also very important that mental health inpatient wards are accessible and appropriate for adults with autism. Untrained staff, noisy and busy environments and a lack of quiet spaces can be very difficult for some adults with autism to cope with, and may exacerbate existing difficulties. We have also heard anecdotally of people with autism learning and copying behaviours such as self-harming methods and behaviours associated with eating disorders in inpatient wards. Autism-trained staff would be more aware of these kinds of dangers and would be better placed to prevent them.

#### Training for professionals, including GPs and mental health professionals

*"It has helped a lot that I wrote up a print out of some of my difficulties using a GP service and gave it to the GP, nurse and receptionist, My GP, having read it, is great about telling me/asking me he needs to touch me and doesn't treat me as stupid when my communication is less good. He also sent a copy of the printout to the physio I am currently seeing and now I'm treated well there too."* An adult with Asperger syndrome

Health professionals, and in particular GPs and mental health professionals, are absolutely integral to adults with autism getting the healthcare they need, and also because of their roles in the referral pathway for diagnosis and support.

The NAO found that 80% of GPs feel they need additional guidance and training to manage patients with autism more effectively<sup>72</sup>. It is clear that this group must be prioritised for training, both through incorporating autism training into their initial professional training syllabus, but also by ensuring it is included in workforce development plans for NHS staff. This training is covered in greater depth in the Training chapter later in this response.

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<sup>72</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

**Summary of recommendations:**

- The annual health checks initiative currently being rolled out to adults with learning disabilities must be extended to include adults with autism who do not have a learning disability
- The Department of Health must develop guidance for healthcare providers to make healthcare more accessible to people with autism, taking sensory needs fully into account
- The strategy should reiterate to healthcare providers their duty under the Disability Discrimination Act to consult adults with autism on all elements of their service, including ensuring that the setting is accessible
- Autism training must be incorporated into the initial professional training syllabus and workplace development plans for GPs, mental health professionals and other NHS staff
- PCT programmes such as IAPT must be made available to adults with autism and comorbid mental health problems, and professionals administering IAPT must be specifically trained to make the necessary adjustments for patients with autism
- Inpatient mental health wards must be made accessible and safe for adults with autism, through ensuring suitability of environment and training staff. DH should issue guidance to inpatient wards to facilitate this.

## Choice and control

### Personalisation

#### Making *Putting People First* work for adults with autism

The NAS is supportive of the principles behind *Putting People First*. Giving control to the individual over how their care budget is spent is an aspiration which we share and endorse.

However, for many adults with autism, personalisation is failing to have the desired impact. There are important aspects of the agenda that have not been designed with autism and other complex needs in mind, and therefore they are falling short for these groups.

A central part of the Government's transformation agenda involves the roll out of individual/personal budgets. The NAS is broadly supportive of the principle of using these new tools to allow people to have more control over their lives, but believe there are some key issues around their implementation. These are:

- i) Lack of information on how individual budgets (IBs) work for people with autism
- ii) Resource Allocation Systems (RAS)
- iii) Support Brokerage
- iv) Marketplace development
- v) Real choice based on accessible information.

These are dealt with in turn below

#### *i) Lack of information on how individual budgets (IBs) work for people with autism*

We have particular concerns about the impact of individual/personal budgets for people with autism. There is very little data and information on how well they can and do work for people with autism. We were told that the evaluation of the individual budget pilot would be "sufficiently detailed" to look at the experiences of adults with autism, but the final report only divided information down into four categories: learning disabilities, mental health, physical/sensory disability and older people. It is unclear where those with autism who took part in the pilot were categorised and discussions with the research team have revealed that it would be difficult to extract information from their existing data about the experiences of people with autism who took part in the pilot.

Moreover, the evaluation report reveals that in a number of pilot sites, those with particularly complex needs were not, at the initial stages at least, selected for inclusion in the pilot, because they were too complex<sup>73</sup>. Those with complex needs face different challenges in receiving individual/personal budgets to others, and if they are considered 'too complex' to be included in the initial pilots this suggests that the systems being piloted were not designed with their needs in mind. There is therefore a real need for

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<sup>73</sup> Glendinning, Caroline et al. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*. York: Social Policy Research Unit. Page 234

the Department of Health to meet its commitment to look at outcomes for people with autism and commission additional research to examine how individual budgets can work for people with autism and those with other complex needs. The evaluation itself recommends further research into the relative merits of IBs for different groups of service users.

The Office for Disability Issues is currently consulting on *Right to Control*, which aims to increase the scope of personalisation to include additional funding streams. The ODI plans to 'trail blaze' *Right to Control* in 2010. It is crucial that lessons are learned from the IB pilots evaluation process, and the ODI takes this opportunity to ensure that this new system of personalisation will work effectively for adults with autism and those with complex needs. The trailblazers must ensure outcomes for adults with autism are able to be evaluated as a distinct category.

#### *ii) Resource Allocation Systems (RAS)*

The way that an individual/personal budget is allocated is absolutely fundamental to its success. There is little point in people being given control of an inadequate budget – this does not give a person the power to shape services to meet their needs. Local authorities must ensure that individual/personal budgets are used to give choice and control to people and not to cut the costs of support. Yet much of the literature on IBs reports that their introduction can result in significant cost savings and further research reveals that the overall losers are people with “higher and more complex needs”<sup>74</sup>.

We therefore have real concerns about the Resource Allocation Systems (RAS) that local authorities are developing to allocate funding as they move towards implementing personal budgets. Any RAS that is produced must take into account the particular needs of people with autism. Our research found that 63% of adults with autism do not have enough support to meet their needs<sup>75</sup>. If the new system fails to address this and fails to allocate sufficient funds, the needs of people with autism will continue to be ignored.

Many people with autism have quite complex needs and there are real questions around whether RAS self assessment surveys, which often comprise of no more than ten questions can truly capture this. We would also challenge whether the use of a standardised questionnaire to allocate funds represents a personalised approach. Indeed, one of the local authorities in the pilots rejected developing a RAS for that reason and instead used an “outcomes focused” approach to resource allocation.

In discussions with Department of Health officials, the NAS has been assured on more than one occasion that the RAS is only intended to be used by local authorities to provide an *indicative* budget, and that a further follow-up assessment is required to be provided to ensure that a sufficient budget is allocated to meet the individual's needs. However, we are aware of many local authorities who are not using the RAS in this way, and are allocating individual budgets strictly based upon the formula used in the RAS. We would urge the Department of Health to issue new guidance to ensure that local

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<sup>74</sup> Clements, L (2008) Individual Budgets and irrational exuberance. *Community Care Law Reports* 11.

<sup>75</sup> Rosenblatt, Mia. (2008) *I Exist: The National Autistic Society*

authorities are aware that the RAS is only intended to be indicative and emphasise the importance of the follow-up assessment.

In conjunction with other disability charities<sup>76</sup> the NAS has produced a document called *Putting Everyone First*. *Putting Everyone First* is designed to help local authorities to think about the needs of people with specific disabilities, including autism, and encourage assessors to ask the right questions to ensure that the budget allocated to the individual is sufficient to meet their needs. The Department of Health should endorse this document and support its distribution to local authorities.

Where local authorities do develop a RAS, we believe it is vital that it is able to determine when higher cost support is required because of the need for specialist support. Some local authorities have said that providing the same questionnaire for all service groups will ensure equity. However, for this equity to be ensured there will need to be a mechanism in the RAS to ensure that greater funds are provided where specially trained support workers are needed. It will be much more expensive, for example, to employ a Personal Assistant (PA) with specialist autism training than it will to employ a PA for someone with less complex needs.

There are also real concerns about an over emphasis on self-assessment. People with autism may answer questions too literally, e.g. if they were asked whether they can make a meal, they may say yes, but omit to mention that this is only with prompting and support from their carer. Moreover, those with complex needs may not have the necessary self-awareness to understand the support they require and consequently they may underestimate the support they need. Consideration is needed about the support that will be given to service users to accurately fill out self assessment forms. Self-assessment questionnaires will need to be piloted with different groups of disabled and older people to ensure they work, before they become a key gateway to accessing support, even if they are followed by a more comprehensive needs assessment.

Questions also need to be asked about the maximum payments to a personal/individual budget that a RAS will naturally impose<sup>77</sup>. Setting a cap is illegal, as eligible community care needs must be met regardless of resources<sup>78</sup>.

### **Case study**

*A young woman with autism and a learning disability was being helped by a voluntary sector self-directed support project worker to move to a new home from a residential college. They had identified some appropriate homes which would support her specific needs, costing between £80,000 and £100,000 per year. However, having had her needs assessed using a RAS she was allocated only £35,000 which was considerably less than she needed to meet her needs. She was not offered a follow-up assessment of her needs and was told that the budget determined using the RAS was final. She is currently attempting to appeal the decision.*

<sup>76</sup> The other charities are Sense, Royal National Institute for Deaf People, Royal National Institute of Blind People, Mencap and Guide Dogs.

<sup>77</sup> A questionnaire that allocates funds on the basis of whether you ticked A,B,C or D on each question will naturally have an upper cap be calculated by adding together the highest number of points that you can get for each question and converting this to pounds.

<sup>78</sup> Clements, L (2008) Individual Budgets and irrational exuberance. *Community Care Law Reports* 11

We welcome the call in the Evaluation of the Individual Budgets Pilot for a national debate on the principles underpinning resource allocation<sup>79</sup> and would very much like to take part in that debate.

### *iii) Support brokerage*

For some people support brokers will be an essential support in a new system, where individual/personal budgets and direct payments become the norm. For this system to work effectively for people with autism, it needs to be ensured that support brokers understand the specific needs and issues faced by this group. The Specialist Autism Team must therefore be accountable for ensuring that appropriate support brokerage is available locally, either through delivering it itself, or by working in conjunction with the voluntary sector. The SAT will have the necessary understanding of the kinds of service that might best meet the needs of adults with autism. They will also have mapped what appropriate services are available in their area and will be able to support adults to access these. It therefore makes sense for the SAT to be accountable for this function.

If people are expected to pay for brokerage from their individual budget or direct payment, additional funds will need to be provided for in the original allocation to pay for this.

### *iv) Market place development*

The Evaluation of the Individual Budgets Pilot flagged up some concerns about the future of the social care market place if individual/personal budgets are to become the norm. Effective and person-centred packages of support can only be developed, where appropriate services are available to buy. Unfortunately, the social care market is distorted through supply side imbalances for people with complex needs<sup>80</sup>.

The Autism Planning Group must ensure that services are commissioned based on the needs and preferences of adults with autism in the local area. Services must be available to reflect the needs of the autism community, such that the support that adults with autism actually want can be purchased using personal/individual budgets and direct payments.

### *v) Real choice based on accessible information*

It is important to remember that not everyone will want to receive their services through individual/personal budgets or direct payments, and that these are entirely optional methods by which to receive support. Individuals must be given a real choice, based on clear, accessible information, on which to make the decision about how they wish to receive their services, be it through a form of personalisation or directly from the local authority.

## Safeguarding and the personalisation agenda

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<sup>79</sup> Glendinning, Caroline et al. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*. York: Social Policy Research Unit.

<sup>80</sup> Clements, L (2008) Individual Budgets and irrational exuberance. *Community Care Law Reports* 11

Safeguarding has been used as a reason in the past to prevent some people from accessing self-directed support. This is something that we would caution against and safeguarding must not be used to prevent people with disabilities from having autonomy and control over their lives. However, robust measures do need to be developed to ensure that vulnerable people are not put at unnecessary risk.

We have substantive concerns about the way that services bought by individual/personal budgets are to be inspected. There is a real risk that vulnerable individuals could be open to abuse if adequate safeguards are not put in place to ensure that personal assistants are properly trained and that the services they provide are properly assessed. Local training plans must ensure that all employers (the local authority itself, individuals accessing support and local care agencies) can access training for their employees.

Clarity is also needed about the lines of responsibility, when something goes wrong with a personal assistant, paid for through a direct payment. We were recently in contact through our email helpline service with a woman with high functioning autism who had a safeguarding complaint in relation to the behaviour of her personal assistants. She had contacted her local Safeguarding Adults Board, but they refused to get involved or give her any support because she paid the personal assistants through a direct payment. The police have not been of help either and she is therefore trying to pursue civil action against them.

This case is particularly demonstrative as it seems that this individual is able: she understands that there has been wrong doing and is pursuing the case as best she can. However, she is unable to use the telephone because of her condition, meaning that in practice pursuing the case is even more challenging. Moreover, the incident has been very distressing for her, particularly as it happened in her own home and there has been no recourse for those involved. Yet those with statutory obligations to provide her with services have turned their back on her. It is therefore essential that Safeguarding Boards support those who pay for services through Direct Payments. This must be made clear to the Boards and to local authorities.

It should also be highlighted that there are risks of abuse from carers and families who help individuals to manage their individual/personal budget. A large number of adult protection lead officers within local authorities, who were interviewed as part of the Evaluation of the Individual Budgets (IBs) Pilot had anecdotal evidence of users of direct payments and possibly IBs being subject to financial abuse from family members or paid carers<sup>81</sup>. A team manager interviewed as part of the evaluation said: *“We identified within the last four months about three or four cases where the personal assistants financially abused the service user”*.

To tackle this, measures need to be developed to help enable people to develop robust circles of support consisting of people from a range of backgrounds. For instance, if someone needs help and support to manage their personal finances they may wish to employ an accountant for a given number of hours per year. Clauses around auditing accounts could be built into the accountant’s contract, thus safeguarding against

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<sup>81</sup> Glendinning, Caroline et al. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*. York: Social Policy Research Unit.

financial abuse. Similarly for other types of abuse a strong and robust circle of support made up of people who have a real interest and regard for the person supported is likely to reduce the risk of abuse occurring. Advocacy would have a central role to play here. Funding for an accountant's time or support from an advocate will have to be built into a person's individual/personal budget. Otherwise, the most vulnerable people who need the most support in managing their own care will be penalised for having higher support needs.

### Person-centred plans based upon aims and aspirations

Services should be built around individual needs, rather than on the assumption that what suits one person will also suit another. While this is true for all people, the diversity and individuality of autism means that no two people will be affected in quite the same way. A person-centred approach is required, which involves listening to the individual and making sure that they are always at the centre of planning and delivering services.

Unfortunately, there is still a long way to go before person-centred planning becomes a reality for adults with autism. Only 27% of adults with autism currently have a person-centred plan or care plan<sup>82</sup>. All adults with autism who are eligible for support must have access to, and be offered, a person-centred plan.

Person-centred plans will also help ensure that risks of abuse can be picked up earlier, as working in a person-centred way, supporters and social workers will have a better understanding of the individual concerned. They should also help to support individuals with autism to develop the skills they need to keep healthy and safe.

### Personal health budgets pilots

Personal health budgets, as will be legislated for through the Health Bill, are currently being piloted. It is very important that lessons are learned from the individual budgets pilots, and that adults with autism are involved in the pilots in such a way that outcomes for this group can be evaluated separately. Otherwise, we will end up with another form of personalised support for which we will have no understanding of how well it works for this group.

#### **Summary of recommendations:**

- The 'trailblazers' for Right to Control, as well as the pilots for personal health budgets, must ensure that outcomes for adults with autism are able to be evaluated as a distinct category
- The Department of Health must issue new guidance on Resource Allocation Systems to emphasise that they are only intended to be used to provide an indicative budget, and that they are to be followed up with a more comprehensive assessment of need. The Department of Health must also support the distribution of the *Putting Everyone First* document

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<sup>82</sup> Rosenblatt, Mia. (2008) / *Exist: The National Autistic Society*

- Local authorities must ensure that resource allocation for individual/personal budgets and direct payments, however it is determined, takes into account the additional costs associated with specialist autism support. Budgets must also cover the costs of necessary brokerage and advocacy
- There must be a national debate on the principles underpinning resource allocation as called for in the Evaluation of the Individual Budgets Pilot
- The SAT must be accountable for ensuring that autism-appropriate support brokerage is available locally, in conjunction with the voluntary sector where appropriate
- The APG must ensure that appropriate services are commissioned locally to reflect the support that individuals wish to buy with their personal/individual budgets and direct payments
- Individuals must be given a clear choice, based on accessible information, as to how they would like to receive their care (i.e. through direct payments, individual budgets or direct from the local authority)
- Local training plans must ensure that all employers, including the local authority itself, individuals accessing support and local care agencies, can access training for their employees
- Safeguarding Boards must support people who pay for services through direct payments
- Local authority must identify mechanisms by which robust support can be put in place to combat financial or other abuse that may occur in purchasing services through direct payments or personal/individual budgets.
- DH to issue robust guidance aimed at local authorities to minimise the risk of abuse to people who employ support through direct payments or individual/personal budgets.
- All adults with autism who are eligible for support must have access to, and be offered, a person-centred plan.

## **Transition**

Transition is a very important time for all disabled young people, but for young people with autism it is especially so. People with autism find coping with change intrinsically difficult, so will find the multiple changes involved during transition a significant challenge. Transition is a crucial time in the lives of all young people. If handled right it can set people up for financial and social independence, while if it fails it can leave people isolated and vulnerable, often with life-long damaging effect.

Local authorities have existing statutory duties to support disabled young people through transition. However, we are aware that transition outcomes for young people

with autism are far from satisfactory. Our research found that only 53% of young people with autism who have statements of special education needs were given a transition plan during the course of their education<sup>83</sup>. This figure falls to just 34% of students in mainstream schools. Transition plans must involve adult social services if they are to be truly helpful, yet we found that adult social services were involved in only 17% of these cases.

This year, the All-Party Parliamentary Group on Autism published a report detailing their Inquiry into transition to adulthood for young people with autism<sup>84</sup>. The NAS supports the findings and conclusions of the report, which was heavily critical of the damage that poor transition planning is causing young people with autism:

*“Such poor transition creates a chasm between the aspirations of young people with autism and the reality experienced by many adults on the autism spectrum. The failures of the system become internalised as the failures of the young people themselves, as they find themselves unemployed and living at home or, in the worst-case scenarios, in prison, or experiencing significant mental health problems. For want of a good transition, a good adulthood for people with autism is being lost.”<sup>85</sup>*

### The transition planning process

Transition plans must start at age 14 for all disabled young people. This long time period is especially important for young people with autism who will struggle with change and will need longer than most to prepare for a new support plan. Although it is already Government policy for this to happen, we have found that this is not the case for many young people with autism, for whom transition feels more like an event than a process.

Transition planning must be aspirational, and the young person must be fully supported to ensure that they are given a strong voice in the process, with support from an independent advocate where necessary. A transition plan must also have a strong employment focus. Employment outcomes for adults with autism are extremely low, and currently only 15% are in paid full-time work<sup>86</sup>. If transition plans consistently incorporated plans to help the young person to find employment (when this is what they want) this would be an important step towards improving this appalling statistic.

Staff involved in transition planning for young people with autism must have a good understanding of autism, based on thorough training. This training would be provided by the SAT.

**Good practice example** (Source: Transition to adulthood, Amanda Allard for the APPGA, June 2009)

*“The children’s team contacted the transition team on my son’s 14<sup>th</sup> birthday. A transition team worker arranged a house visit immediately, to discuss possibilities for*

<sup>83</sup> Batten, A. Make School Make Sense, NAS (2006)

<sup>84</sup> Transition to adulthood, Amanda Allard for the APPGA (June 2009)

<sup>85</sup> Transition to adulthood, Amanda Allard for the APPGA (June 2009)

<sup>86</sup> Reid, B. (2006) *Moving on up? Negotiating the transition to adulthood for young people with autism*. London: NAS.

*adult placements. An information pack on local facilities was left for us to consult. An adult learning disability social worker was chosen within two months, to match our son, and visited the house to agree the places chosen.*

*“The social worker spent the day on two boarding school annual reviews, between 14 and 18, seeing out son alone for one hour each time, to get the feel [of him] and become familiar to him. He also drove down with us, to get to know us (95 miles). When our son was suddenly excluded from school at 17, the social worker visited our house, again spending time alone with him, and we rushed forward the plans for transition. Our son was relaxed, as he knew and trusted the guy. He transferred to a local horticultural training scheme within four months.”*

### Local transition leads

The Government has recognised that transition can be an especially challenging time for young people with autism and has commissioned research into transition and autism. We very much welcome this development, and also the autism focus in the current Transition Support Programme. The findings from the transition research and from the evaluation of the Transition Support Programme, when they are completed, must be translated into action. This could be best achieved by incorporating them into a revised adult autism strategy.

A further welcome development, through Valuing People Now, is the introduction of transition leads for young people with a learning disability in every local authority. However, young people with autism who do not have a learning disability are equally in need of this support. Therefore young people with autism must be provided with equivalent transition leads, such that those young people with autism who do not have a learning disability are also supported.

### SEN statements and transition

The *SEN code of practice* states that young people without an SEN statement should have access to support and advice during the transition period, but there is no legal requirement for a transition review or planning to take place. This can leave many young people and their families having to make arrangements for transition without adequate planning support from relevant agencies.

Additionally, many local authorities are trying to reduce their reliance on statements to support children with special educational needs in line with Government policy. An unintended consequence of this is that pupils who may previously have received transition planning and support automatically as part of their statement may now struggle to access this support.

Statutory duties must be extended to include all children with autism who are supported through School Action Plus, regardless of whether or not they have a statement. As more schools move towards using School Action Plus rather than SEN statements, it is essential that local authorities have a statutory duty to support these children through the transition process.

## Transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services

The NAS held focus groups this year with parents of children and young people with autism and mental ill health. We spoke to 11 parents whose children were between 14 and 19, all of whom told us that their child had not gone through any transition planning with CAMHS. All were extremely concerned about what support their children would receive when they left CAMHS.

Young people with autism *and* mental ill health are among the most vulnerable in the country, and it is absolutely crucial that the right support is put in place for them as they reach adulthood. The Government must require CAMHS to carry out transition planning for children receiving mental health services from age 14. The planning must include regular meetings with adult mental health services to ensure a smooth transition from child to adult services. Where those individuals do not meet the referral criteria for an adult mental health team, measures should be put in place to support them through alternative services. The APG must be informed of gaps in this provision where they exist.

### Transition and strategic planning

Improved data-collection and sharing is also a necessary part of improving the transition process. Directors of Children's Services must be given a duty to maintain an accurate database of the numbers of children with autism in the local area, which must be shared with the Director of Adult Services and the Autism Planning Group to help ensure that service development and planning is carried out effectively.

At least one person from children's services must attend APG meetings to update the group on young people with autism reaching adulthood, and the transition plans are being agreed for future support. This way, the APG can work to ensure that services exist to support this group when they reach adulthood.

### Transition at other stages of life

As people with autism generally struggle to cope well with change, support for adults with autism going through change at any point in their life should be factored into person-centred plans.

The principles of:

- sharing information between agencies
- developing person-centred transition plans
- providing accessible information about options alongside communication support, and
- being given the opportunity to try choices out before making decisions

should all apply to any transition that an individual may go through at any point in their lives. Person-centred plans for adults with autism must take into account the difficulties that adults with autism are likely to face with transitions in adulthood, for example

movement in and out of services, staff changes or bereavement. Plans must include provision of appropriate support to make these transitions as easy as possible.

#### **Summary of recommendations:**

- Local authorities must be reminded of their existing duties around transition, including starting transition plans at age 14, and basing them on the aspirations of the young person. They must include a strong employment focus and be carried out by staff trained in autism
- Young people with autism must be provided with transition support leads, like those introduced to support young people with learning disabilities.
- Statutory duties around transition must be extended to include all children who are supported through School Action Plus.
- CAMHS must be required to carry out transition planning for children using their services. Where children are unlikely to meet referral criteria for an adult mental health team, measures should be put in place to support them through alternative services.
- At least one person from children's services must attend Autism Planning Group meetings to ensure that gaps in provision for children currently going through transition are identified and commissioned.
- Directors of Children's Services must be given a duty to maintain an accurate database of the numbers of children with autism in the local area, which must be shared with the Director of Adult Services and the APG to ensure effective service development.
- The specific difficulties faced by adults with autism with regard to transitions that occur during adulthood must be recognised in person-centred plans, with appropriate support put in place.

#### **Advocacy**

Advocacy is an extremely important part of service-provision for adults with autism. The 'triad of impairments' which are integral to autism – social communication, social interaction and social imagination – can make it very difficult for adults with autism to express themselves as they wish to. They may find it hard to talk to unfamiliar people or find it hard to engage with people in unfamiliar surroundings or situations. They may find it harder to communicate their aspirations and may find it hard to answer questions that they were not expecting. Others, and in particular those with a learning disability, may have difficulty understanding their rights. It is therefore important that any adult with autism who needs one can access an independent advocate who can help them to speak up for themselves and help them to access the support that they are entitled to.

This service must be free to access for the individual. If individuals are using personal/individual budgets or direct payments, money for these services must be factored in as part of their allocated budget.

Advocates must be autism-trained

*"I can't believe that I have been expected to work with people with autism for years without the information I have gained today. It is so unfair on my clients and on me."*

*"This training has been so important, it has been frustrating to have to wait so long due to lack of capacity to run more courses."*

*"The difficulties that I have had with previous clients now make sense, and I feel that I can work differently."*

Quotes from professional advocates on completing Department of Health funded NAS autism-specific advocacy training

As demonstrated by the above quotes, autism training is essential for any professional advocate working with adults with autism. In advocating for an adult with autism there are many very important factors to consider, both in terms of the individual's needs in terms of helping them to think about what support they might want, and in terms of effectively supporting the individual to get that support in terms of communication and other support needs. Without thorough training it is a very tall order to expect an advocate to be have an adequate understanding of these things, which is both unfair on the advocate and the individual.

The SAT should ensure that this training is provided to local advocacy services so that they are able to properly support adults with autism. Furthermore, the national qualification on advocacy must cover autism and the communication needs of people with autism. The SAT should also support the development of local advocacy and self-advocacy groups.

**Summary of recommendations:**

- Advocacy must be made available to all adults with autism and must be free for the individual to access.
- All advocates expected to work with people with autism must be appropriately autism trained. The national qualification on advocacy must cover autism and the communication needs of people with autism.
- The SAT should support the development of local advocacy and self-advocacy groups

## **Involvement and participation of adults with autism**

### The Disability Equality Duty

Under the Disability Equality Duty (DED), all public bodies have an existing duty to involve people with disabilities in their planning and decision making processes in order to ensure that they are not discriminating against disabled people.

It is important that adults with autism, their families and carers and self-advocacy groups are involved in the DED process. This is a key part of ensuring that public services and buildings are accessible to people with autism – people with autism have very specific needs which are only likely to be given due consideration if the people affected are involved in decision-making processes from the start.

This duty already exists, but it is important that the strategy emphasises the need for DEDs to specifically include people with autism and their families and carers, to further ensure that public bodies adhere to this duty.

Furthermore, any consultation documents must be made available in accessible formats such as plain English and easy-read, and any consultation events must be planned taking into account any reasonable adjustments that may need to be made to enable adults with autism to take part.

Disability discrimination legislation is set to change through the introduction of the Equality Bill. It is important that if / when it changes, the existing duty to involve disabled people in local decision making remains.

### The External Reference Group must be retained

DH have established an External Reference Group to help guarantee that the wide range of circumstances and experiences of those who are affected by or work in autism have been given full consideration in producing the adult autism strategy. The ERG has been an invaluable part of the process and will have contributed a great deal to the content and shape of the strategy.

The NAS would very much like to see the ERG retained in some capacity as the strategy is introduced and moves forwards. They would monitor the impact of the strategy in its maiden years and act as an advisory board if the strategy was not having the desired impact.

#### **Summary of recommendations:**

- The strategy must emphasise the need for public bodies to specifically involve people with autism, their families and carers, in meeting their responsibilities under the DED. Any consultation documents or events must be fully accessible to people with autism.
- The Department of Health retain the strategy External Reference Group to monitor implementation of the strategy and act as an advisory board.

## Access to training and employment

NAS research found that whilst many people with autism want to work just 15% of adults with autism in England are in full time paid employment<sup>87</sup>. Furthermore, the same research also revealed that over 60% of adults with autism rely on their families for financial support, implying that for those not in work, the benefit system is also failing to meet their needs. Autism is a spectrum condition, everyone is different and whilst it is important that all people with autism are given the chance to work, be that paid or voluntary, it is also vital that the benefits system meets the needs of all those reliant on it.

Public Service Agreement (PSA) 16 work is addressing the employment needs of people with a learning disability and an employment strategy is due to be published soon for people with mental ill health. Despite the inclusion of autism and Asperger syndrome in PSA 16 there has not yet been any action taken to address this. It is therefore vital that the Adult Autism Strategy contains a strong focus on employment to secure substantial change for people with autism seeking work.

The issue can be split into three core areas. Adults with autism need support:

- accessing the benefits system
- preparing for and finding work
- in employment

### Accessing the benefits system

A recent National Audit Office report revealed that the experiences of adults with autism accessing the benefits system are mixed<sup>88</sup>. In some cases people felt that the system recognised autism and understood their needs. For others, the staff they met had little or no knowledge of autism. It is vital that the benefits system works for all people with autism and there are several simple steps that can be taken to achieve this.

### Communication and access to information

#### *Awareness of benefits*

The fact that there are large numbers of people with autism not in work and financially reliant on their families indicates low awareness of benefit entitlement among people with autism. The Department for Work and Pensions needs to address this through awareness raising measures targeted at people with autism.

#### *Communication*

Autism is a communication disability so it is therefore vital that from a person's very first contact with the Department for Work and Pensions they are asked about their autism and appropriate adjustments are made. Failure to make these adjustments can adversely impact upon a person's ability to access benefits. For example, in the initial application for Employment and Support Allowance an individual is asked if they are too sick to work. People with autism often interpret things literally, and an individual could

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<sup>87</sup> Rosenblatt, M. (2008) I Exist, The National Autistic Society

<sup>88</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

therefore respond in the negative and be referred for the wrong benefit. This demonstrates how small adjustments to language can make an enormous difference to an adult with autism's ability to access benefits. It is therefore crucial that staff involved in the benefit application process ask early about whether the individual has autism, and are sufficiently trained in communicating with adults with autism to continue with their application<sup>89</sup>.

### *Advocacy*

As people with autism apply for benefits, right at the start of their claim they must be informed of their right to an advocate, be that a friend or family member or an independent advocate. Those people who want an independent advocate should be supported to access one. As explained in the Choice and Control chapter, advocates can be an essential part of enabling people with autism to communicate, especially in unfamiliar situations or to people they do not know well. Accessing an advocate would help address any communication difficulties, making it easier for people with autism to access the benefits they need.

### Medical assessments

#### *Sick notes*

For those applying for Employment and Support Allowance, sick notes can present a real challenge to accessing the benefit. Doctors regularly refuse to issue sick notes to patients with life long conditions or in some cases feel it is not appropriate to issue them beyond six months, leaving families to request a repeat sick note every six months. Autism is a lifelong condition and the use of sick notes in applying for Employment and Support Allowance adds an unnecessary layer of bureaucracy and a further barrier to those seeking to access the support this benefit provides. We therefore recommend that sick notes are scrapped for people applying for ESA.

#### *Medical assessments*

It is important that the medical assessment for Employment and Support Allowance works for people with autism. Employment and Support Allowance sees the old Personal Capability Assessment that was used for Incapacity Benefit replaced with the new Work Capability Assessment. This takes much better account of autism and as it is revised it is important that this continues to be the case.

It is also necessary that those tasked with carrying out the medical assessments, Atos doctors and nurses, are sufficiently trained in autism. Due to the communication barriers facing people with autism, if an assessment is not carried out by someone with an understanding of autism, with appropriate adjustments made to communication, then it risks an inaccurate medical report.

### Sanctions

Sanctions are now part of both Jobseeker's Allowance and Employment and Support Allowance, and pose a real risk for people with autism. As autism is a communication disability, there is a danger that people with autism will not always understand the threat of sanctions, even when these are explained to them. We would therefore recommend

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<sup>89</sup> See Appendix 3

the immediate implementation of Professor Paul Gregg's recommendation that the first sanction for benefit claimants is replaced by a written warning. This would be a step towards ensuring that whilst still acting as a deterrent to those seeking to exploit the benefit system, sanctions would not unfairly penalise those with more complex needs.

Further safeguards would be added by ensuring that all written communications that concern sanctions or meetings at Jobcentre Plus are automatically provided in easy read and plain English formats. This will help to ensure that people with autism understand the conditionality regime that now goes with JSA and ESA.

### Disability Living Allowance

Many people with autism feel that the adult DLA form, with a strong focus on physical disabilities, fails to take account of the needs of people with autism. It also fails to recognise the mobility problems that people with autism may experience due to the stress and anxiety that travel/outside spaces can cause. This is further compounded by the need for improved training in autism for DLA decision makers.

There are also real concerns that the new checklist being introduced for working age DLA will deter many people with autism from applying for the benefit. The checklist has a strong physical focus which will make it difficult for people with autism to understand how DLA applies to them. The checklist should be abolished as it provides an artificial barrier to DLA for adults with autism.

### **Summary of recommendations**

- The Department for Work and Pensions must take action to improve awareness of entitlement to benefits among adults with autism
- Staff involved in the benefit application process must be sufficiently trained to communicate with adults with autism
- Everyone applying for ESA must be informed of their right to an advocate and for those who want an independent advocate they must be supported to access one
- Sick notes for ESA should be scrapped
- Atos doctors must be sufficiently trained in autism to carry out Work Capability Assessments.
- Professor Paul Gregg's recommendation that the first sanction for benefit claimants be replaced by a written warning should be implemented straight away.
- All written communications that concern sanctions or meetings at Jobcentre Plus to be automatically provided in easy read and plain English formats.
- Working age DLA forms must be revised to recognise the care and mobility needs of people with autism. The DLA checklist must be abolished.

## Preparing for and finding work

People with autism face a range of challenges accessing the workplace, such as:

- They can find it difficult to understand job advertisements which include confusing jargon, or they may be put off applying for jobs that stipulate skills not needed for the role. For instance, a technical job that requires minimal team work may still request “strong interpersonal skills” or “excellent teamwork” in the person specification.
- At job interviews people with autism may find it hard to answer open-ended questions such as “Tell me about yourself”, or can take questions literally and give ‘yes’ and ‘no’ answers to questions such as “Can you tell me about your work experience?”
- Interviews can also be difficult as people with autism can have difficulties understanding body language and with making eye contact.

These difficulties often mean that support is necessary for adults with autism to access the workplace. The main source of this support is Jobcentre Plus, but respondents to recent National Audit Office research felt that advisors at Jobcentre Plus were not always aware of autism, leading to inadequate support<sup>90</sup>.

More needs to be done to ensure that adults with autism are given the support many need to move into work.

### Improving employment support during transition

Transition is a key time to ensure that young people with autism get the right support to prepare for the workplace. This preparation needs to start at school and college. All young people with autism must have the opportunity to undertake work experience placements. Where young people have transition plans, these must include work targets.

### Improving staff training within Jobcentre Plus

We welcome the fact that since November 2005 the Department for Work and Pensions (DWP) has included autism training for all new Disability Employment Advisors (DEAs). However, poor experiences of adults with autism with DEAs demonstrate that more still needs to be done to ensure that DEAs are equipped with the skills necessary to support people with autism. It is of particular concern that as yet only half of DEAs have received the new training. We recommend that the DWP make it a priority to ensure that all existing DEAs receive the new training.

Whilst DEA training in autism is a positive development, Personal Advisors will be the first point of contact for people with autism at the Jobcentre. It is therefore vital that all Personal Advisors are also provided with training in autism. This should include recognising autism, advice on how to best communicate with and deliver support to adults with autism, and how to refer people on to more specialist provision.

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<sup>90</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

## Introducing Autism Coordinators within Jobcentre Plus

In addition to building awareness and knowledge levels amongst Jobcentre staff, it is important that both Personal Advisers and DEAs can access help and advice when working with individuals with autism who have complex needs. Autism is a complicated condition, which presents differently in each individual. Whilst Jobcentre Plus staff currently receive limited autism training, we recognise that not everyone will be able to become sufficiently expert in autism to work with a wide range of clients.

The practical solution is to develop a recognised point of expertise within each Jobcentre. This would provide a clear means for Jobcentre Plus staff to access more advanced advice or support when working with adults with autism. The Department for Work and Pensions has recognised the value of creating a focus of expertise within the system for mental illness with the introduction of mental health coordinators. We would therefore recommend a comparable approach for autism, with a network of Autism Coordinators, who would provide a tertiary level of expertise and resources to Jobcentres in a specified region. Despite the lower prevalence rate of autism in comparison to mental illness, the alarmingly low employment rate of people with autism shows that there is clear demand for greater expertise within Jobcentre Plus.

Autism Coordinators would:

- provide a clear source of information, advice and training to Jobcentre Plus staff
- link Jobcentres to local advocacy services and autism organisations
- increase awareness and understanding of autism amongst local employers.

We would recommend Autism Coordinators to work closely with Specialist Autism Teams, who will themselves have a focus on employment. This will ensure a joined up approach to supporting people with autism into work.

### **Good practice example: Remploy**

Remploy has formed a partnership with the National Autistic Society's employment service, Prospects, to deliver training for Remploy staff and improve referrals. So far staff in Remploy's London branches have received autism training and each branch will have an advisor who will specialise in autism.

## Improving data collection and analysis

For those in receipt of Incapacity Benefit or Employment and Support Allowance, support is available through Pathways to Work and the Department for Work and Pensions needs to make sure that Pathways works for people with autism. This should be achieved by annually analysing data on people with autism supported into work by Pathways, and using this data to help determine the effectiveness of contracts and identify future training needs.

## Specialist support

Specialist autism support, delivered through either Workstep or Work Preparation (soon to become Work Choice) is proven to make a real difference to people with autism. The

NAS delivers employment support through its own specialist service and independent research has shown that it has a 68% success rate<sup>91</sup>.

However, changes to the way the DWP provides this support risk jeopardising specialist provision. Contracts need to allow for the fact that some individuals will cost more to support into work than others to avoid people with autism being ignored by large, prime providers and to ensure that specialists can afford to continue delivering support. Once contracts have been awarded, data needs to be collected and published on the numbers of people with autism supported into work by each provider to demonstrate how effective it is for people with autism. As plans for the introduction of Work Choice progress, the Department for Work and Pensions must ensure that the new programme works for people with autism.

### **Case study: effective support preparing for and finding work**

*Joe received support from an employment service for people with autism. Joe attended weekly group workshops on various subjects such as coping at work, facing the future, workplace relationships, and healthy living. Joe also attended one-to-one sessions every week where he focused on areas which he felt he needed to improve in, in particular conversation skills and how to interpret body language.*

*Joe had always wanted to work in a supermarket. He began applying for positions and when he was invited to an interview his support worker from the autism employment service accompanied Joe to the interview and also spoke to the supermarket about Asperger syndrome and the support that the employment service could provide. Joe was then offered an eight-week placement as a store assistant.*

*Joe's support worker visited him weekly during his placement and talked to both Joe and his supervisor about any problems that had arisen. Joe's supervisor was extremely pleased with his work and on the last day of Joe's placement he was offered a full time position. Joe continues to attend the employment service to work on the skills that will enable him to succeed in the workplace.*

### **Summary of recommendations**

- Connexions should ensure that transition plans for young people with autism have an employment focus, including seeking opportunities for work experience.
- All existing DEAs who did not receive autism training on starting the job should be given the new training as a priority
- Personal Advisers within Jobcentre Plus must be autism trained
- Autism Coordinators must be introduced to Jobcentres to ensure that there is a clear source of autism information and advice available to all Jobcentre Plus staff, to increase awareness of autism among local employers and to join up existing autism services within an area.

<sup>91</sup> Howlin P, Alcock J, Burkin C, 'An 8 year follow-up of a specialist support employment service for high-ability adults with autism or Asperger syndrome' in *Autism* 9(5) (2005).

- SATs must have an employment focus to ensure that people with autism are given the right support to find employment.
- Data must be collected and analysed annually on outcomes for adults with autism using Pathways to Work and Workstep / Work Preparation (soon to become Work Choice).
- The Department for Work and Pensions must make sure that contracts for Work Choice include specific requirements for supporting adults with autism.
- Ofsted inspections must identify how well provision works for adults with autism.

## **Supporting adults with autism in employment**

People with autism can struggle in the workplace, and may:

- Find it hard to recognise and understand other people's feelings and express their own, making it difficult for them to 'fit in' with their colleagues. Many may want to make friends, but may be unsure how to go about this. For example, all jobs have mutually understood unwritten rules and expectations, such as making tea and coffee for everyone if having one yourself. A person with autism may not grasp these unwritten rules unless they are explained to them.
- Need clear guidance of what is expected, for example, instead of saying 'Make sure everybody has a copy of this' say 'Photocopy this three times and give the copies to Mary, Sam and Ahmed.'
- Find it difficult to plan their time and need help structuring their day.

### Access to Work

Access to Work can make a real difference when it comes to supporting people with autism in the workplace. However, this relies upon Access to Work assessors having a good understanding of autism and the impact it can have in the workplace. In particular Access to Work staff need to be more aware of the non-physical adjustments that people may need. Access to Work assessors must be given appropriate levels of autism training and Access to Work publicity must stress to employers that the scheme can help with non-physical adaptations and support.

### Reasonable adjustments

The Department for Work and Pensions must issue guidance as to the reasonable adjustments employers can make for people with autism. This would help improve the recruitment process for people with autism and open up more employment opportunities through advancing understanding among employers of the things they can do, which are usually very simple, to make their workplace more accessible.

Autism Coordinators have a key role to play in raising awareness of autism among, and developing relationships with, local employers.

## Targets for Government Departments

In *Valuing Employment Now* the Department of Health set targets for Government Departments to employ people with a learning disability<sup>92</sup>. The adult autism strategy provides an opportunity to set similar targets for employing people with autism. The NAS strongly recommends that this opportunity is taken. This would demonstrate that Government is taking employing adults with autism as seriously as employing adults with a learning disability.

Indeed, in giving evidence to the Public Accounts Committee<sup>93</sup> Mr. Hugh Taylor, Permanent Secretary at the Department of Health, committed to employing more people with autism:

*“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.”*

This is a very welcome commitment given that DH and the NHS are among the country’s largest employers. It is essential that this strong commitment is reflected with an employment target in the strategy.

### **Case study: in work support**

*Yusef, a young man who has Asperger syndrome, started work as a stamping and labeling assistant at a library, whilst being supported by an autism employment service. Although he has very good language skills, these mask the difficulties he has understanding the social situations he finds himself in. This can lead to Yusef acting inappropriately or talking excessively about a subject - for instance, a significant proportion of his conversation consist of him recounting lists, which Yusef manages to introduce into the discussion.*

*It was therefore important to put strategies in place to enable Yusef overcome this; he would otherwise not be able to concentrate long enough to work effectively, and would risk alienating other co-workers*

*Another key task was to train and enable Yusef’s new colleagues to set boundaries and rules for him. For example, it was agreed that they would tell him, pleasantly but clearly, when it was time to stop talking and get back to work. Yusef has now settled down well into his job, and his colleagues have reported that after initially feeling uncomfortable in being verbally direct with him they have subsequently found this approach to be beneficial for both them and him.*

### **Summary of recommendations**

- Access to Work assessors must be given appropriate levels of autism training.

<sup>92</sup> *Valuing employment now - real jobs for people with learning disabilities* (2009) Department of Health

<sup>93</sup> Public Accounts Committee Hearing, House of Commons, 15 June 2009 ...

- Access to Work publicity must stress to employers that the scheme can help with non-physical adaptations and support.
- The Department for Work and Pensions must issue guidance as to the reasonable adjustments employers can make for people with autism. Autism Coordinators have a key role to play in raising awareness of autism among, and developing relationships with, local employers.
- The Department of Health must set targets for Government Departments to employ people with autism.
- DH must act on the commitment to the Public Accounts Committee to be an exemplar in employing adults with autism.

### **Access to further education**

Accessing appropriate opportunities in further education is essential for many adults with autism to reach their full potential. Yet when it comes to management of the difficulties associated with autism, there is nothing near the equivalent of the support that is available at for children at school being made available to adults wishing to access education services.

Adults with autism will often need specialist support or tuition to access education. The NAS has been made aware of people being placed into training or education which is inappropriate for them simply because it is available, with little or no regard for what they might get out of it. The Autism Planning Group should therefore include within its remit the need to ensure that appropriate further education courses are available locally.

People with autism must have access to further education courses that include the teaching and training of those independent living skills which they may struggle to acquire informally. Skills such as how to cope with everyday independent living (including the management of money and budgeting), how to cope with people and relationships, dealing with emotional states and work and interview skills must be covered by further education courses.

For those who require it, the curriculum should include self-help and living skills as well as more specific social skills (including relationships and sex education), and interview and presentation skills. They should also make available training in emotional management, including techniques and strategies, such as relaxation training, but also emotional literacy, teaching the student to identify and describe internal feelings.

Post-16 education providers would benefit greatly from an improved understanding of autism and its effect on adults in an educational setting. Training for relevant staff would make a big difference, and the levels to which these staff should be trained can be found in Appendix 3.

**Summary of recommendations**

- The Autism Planning Group should include within its remit the need to ensure that appropriate further education courses are available locally.
- Further education curricula must include the teaching and training of independent living skills for students with autism
- Staff working at post-16 education providers should be trained to appropriate levels (see appendix 3)

## Awareness raising and training

Training and awareness among professionals is at the heart of achieving equality for adults with autism. Many of the difficulties experienced by adults with autism are a result of a lack of understanding of autism among staff working in local services. Professionals are often confused or unaware about the complexity of autism and the many different ways it can affect people. Many have had very limited training in the condition, and some have had none at all. Our research found that 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<sup>94</sup>.

### Training needs of key professionals

#### Professionals carrying out needs assessments

Typically, a lack of understanding of autism leads to false assumptions being made about the needs of adults by professionals carrying out needs assessments. These include community care assessments, FACS assessments, NHS continuing care assessments or carers assessments. A common misunderstanding is that adults with autism who have an average or above average IQ do not experience considerable difficulties because of their autism. This is certainly not the case – adults with high-functioning autism or Asperger syndrome will often be academically very able, but may struggle to manage straightforward, everyday tasks, such as using public transport or cooking.

Adults who have autism and an accompanying learning disability also fall victim to a lack of understanding among professionals. Some learning disability services will be inappropriate for an adult with autism, due to the sensory environment for instance. Due to a lack of training, social workers often place adults with autism and a learning disability in inappropriate services, which can cause great anxiety and stress to the individual, and may ultimately result in additional support needs being acquired. Training is therefore particularly important among those professionals who carry out care assessments, as they will in most cases act as the gateway for support.

Worryingly, our research found that local authorities do not think that care managers receive sufficient training in autism in their initial professional training (71%) and in their ongoing professional training (67%)<sup>95</sup>. Similarly, the NAO found that only 29% of local authorities' training programmes for staff who carry out FACS assessments covered high-functioning autism<sup>96</sup>. It is essential that whoever is conducting a needs assessment has an understanding of the nature of the disability and that they know how to communicate with someone with autism in order to assess their needs properly and fairly. As explained in the Social inclusion chapter, this will include consideration being given to an individual's preferred method of communication, setting up meetings at times that suit them, providing access to an advocate and involving people who know the individual. It is also crucial that these professionals are able to understand the difficulty some people with autism have in defining what their needs and aspirations are;

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<sup>94</sup> Think Differently, Act Positively, NAS 2008

<sup>95</sup> Rosenblatt, Mia. (2008) *I Exist: The National Autistic Society*

<sup>96</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

for example, some people with autism might not recognise or be able to explain their needs, or might answer a question in a way that they think the assessor wants them to.

The NAO recommend that those professionals involved in such assessments are suitably trained in autism, or that they seek support to carry out assessments where they are not trained. We strongly support this recommendation – as explained previously in this response, the SAT would take the lead on both training assessors and supporting those assessors who lack the necessary expertise.

### Training for GPs and mental health professionals

Research from the NAO found that 80% of GPs feel they need additional guidance and training to manage patients with autism more effectively<sup>97</sup>. GPs have an absolutely critical role to play in identifying and referring adults with autism for diagnosis. With better training and awareness among frontline professionals, many more adults with autism will become known to services and will be more likely to receive the support that they need.

Furthermore, there is a need for training among GPs and mental health professionals to ensure that adults with autism receive the right intervention. Without a sound understanding of autism, medical professionals can offer interventions that are at best unhelpful and at worst dangerous. We are aware of cases in which autism has been ‘treated’ either with inappropriate drugs or unsuitable advice, which can worsen the impact of autism on the individual or lead to additional mental health problems developing.

Some of the behaviours associated with autism, like sleeping difficulties, personal obsessions, rituals and the need for routine, can easily be interpreted as a mental health disorder to the untrained eye, or in some instances possible indicators of abuse. It is important that professionals have an understanding of autism in order to identify the reason behind the behaviour, make an accurate diagnosis, and recommend appropriate treatment or support when or if necessary. Misdiagnosis will inevitably lead to inappropriate provision and existing problems will continue or worsen.

In some cases a lack of understanding of autism leads to professionals ignoring the autism (whether diagnosed or not) such that only the non-autism aspects, often mental health problems, of an individual’s difficulties are addressed. If the underlying difficulties relating to autism are not addressed then the mental health problems are very likely to reoccur.

People with autism also have a high rate of comorbidity, i.e. they will often also have a mental health condition unrelated to their autism. Our research found that 33% of adults have developed additional mental health needs because of a lack of support<sup>98</sup>. Research from the Office of National Statistics reported that 30% of children with autism had another clinically recognisable mental disorder, as compared to 10% of all children and young people<sup>99</sup>. In a more recent study of children with autism between the ages of 12-14, researchers found that 70% of participants had at least one co-morbid disorder,

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<sup>97</sup> Clark et al. (2009) *Supporting people with autism through adulthood*, The National Audit Office

<sup>98</sup> Rosenblatt, Mia. (2008) *I Exist*: The National Autistic Society

<sup>99</sup> Green et al (2005), *Mental health of children and young people in Great Britain in 2004*, (ONS: London)

while 41% had two or more, such as social anxiety disorder, attention deficit and hyperactivity disorder or depression<sup>100</sup>. Research of this type has not been carried out for adults but it is safe to assume that prevalence among this group is similarly high.

Additional conditions are often overlooked by professionals through what is sometimes described as 'diagnostic overshadowing'. This is where because of a primary diagnosis of autism, other conditions are left undiagnosed and are seen as 'part of the autism'. This can be because of a failure to carry out a full assessment and this will often be as a result of a lack of understanding of autism on the part of professionals.

The Royal College of Psychiatrists, in their report "Psychiatric services for adolescents and adults with Asperger syndrome and other autistic spectrum disorders"<sup>101</sup>, have recommended that psychiatric training must include experience in the diagnosis, assessment and management of individuals with autism. They explain that given the complexity of the diagnostic process, there should be supervised experience with adults with autism as part of the training and continuing development of psychiatrists.

### Training for employment professionals

Our survey showed that just 15% of people with autism are in full-time employment. Changes to Jobseeker's Allowance and the introduction of Employment and Support Allowance mean that there is an increased focus on everyone, except those with the most complex needs, preparing or looking for work. It is therefore vital that all those tasked with delivering support through Flexible New Deal, Pathways to Work and Work Choice understand the particular support needs of people with autism and have the necessary skills to meet these.

### Initial professional training for future workforce

For key professionals in health, social care and employment services, the Department of Health and Department of Work and Pensions must ensure that autism training is incorporated into the initial professional training syllabus. This will ensure that those professionals whose day-to-day jobs will have a regular and significant impact on adults with autism will be sufficiently autism-trained upon starting their jobs.

The following professionals in health, social care and employment whose jobs impact sufficiently upon the lives of adults with autism such that autism must be included in their initial professional training syllabus:

#### *Health:*

- GPs
- Psychiatrists, psychologists and other mental health staff
- Nurses
- NHS Continuing Care Assessors
- Speech and language therapists and occupational therapists

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<sup>100</sup> (Simonoff, Pickles, Charman, Chandler, Loucas and Baird 2008)

<sup>101</sup> The Royal College of Psychiatrists (April 2006), *Psychiatric Services for Adolescents and Adults with Asperger Syndrome and Other Autistic-Spectrum Disorders*

- PCT commissioners
- CQC inspectors

*Social care:*

- Social workers
- Staff who carry out community care and FACS assessors
- Personal assistants
- Local Authority commissioners
- Advocates (including IMCAs)
- Social care brokers
- Social care support staff/care workers
- Care providers
- CQC inspectors

*Employment services:*

- Disability Employment Advisors
- Personal advisers within Jobcentre Plus
- Work capability assessors
- Atos medical professionals
- Decision makers
- Connexions staff
- Staff involved in delivery of Pathways to Work and Work Choice
- Access to Work assessors

Appendix 3 details the essential and desirable levels of training that each of these professionals should be required to reach.

**National strategy to deliver autism training to existing staff**

Appendix 3 at the end of this response details a comprehensive (but not exhaustive) list of staff who need some level of autism training and outlines the essential and desirable levels of training each of these staff would require. This should form the basis of a cross-Department national training strategy to ensure that all staff whose roles impact upon adults with autism are given an appropriate and proportionate level of training.

Including autism training within initial professional training syllabuses, as outlined above, is a very important step. However, this will only help to reach future staff and will not target existing professionals. Therefore additional measures must be taken to ensure that all relevant staff receive training.

Public sector workforce development plans

In order to ensure that existing staff are covered by training, the adult autism strategy should require workforce development plans for public sector professionals to include autism training. This should include all relevant public sector staff, and would correlate to the training requirements of those staff outlined in the training plan in Appendix 3. So healthcare professionals, local authority professionals, employment service and benefits

professionals, relevant housing staff, those working in the criminal justice system, public transport staff, further education professionals and more would need to be included.

### Improving awareness training in public and private workplaces

There is a need for greater awareness of autism among employers in both large and small organisations. Autism Coordinators have a key role to play in increasing capacity and helping employers identify suitable positions for people with autism.

### Produce training resources

The Department of Health should fund training and awareness-raising resources to be developed and distributed locally. This would be supported by a web-based resource.

It is important that training needs are identified and addressed at a local level as well as national. But it is also important that this training has a degree of consistency about how it is delivered. A comprehensive pack to be used for local training and awareness-raising would help to guarantee this consistency.

The pack should include items that can be used for basic awareness-raising activity, such as a DVD within accompanying discussion guide. It should also include materials to facilitate higher level training, up to and including Tiers 1 and 2 as set out below.

### National training strategy must include plans to increase numbers of diagnosticians

There is a worrying lack of professionals who are qualified to diagnose adults with autism in the country. This is explored in greater detail in the Health chapter. The Government therefore needs to invest heavily in a training scheme to ensure more professionals gain the skills to diagnose autism in adults. If the Government is serious about improving diagnosis rates to provide support to more adults with autism, it must invest to increase capacity in this discipline.

### Local training strategies

Each local APG must develop and deliver a training strategy at a local level. The local strategy would aim to identify skills and knowledge gaps among professionals and commission training appropriately. The local strategy would compliment the central Government strategy, basing competency expectations on the standards set in the national training strategy (outlined in Appendix 2) and working to increase awareness, knowledge and expertise where gaps exist locally.

Some of this training would be carried out by the Specialist Autism Team, in particular training of professionals who carry out care assessments would be carried out by this team. Training of other social workers, care providers, mental health professionals and GPs might also be carried out by the SAT. Training plans should be developed in conjunction with people with autism and their families.

To support this work, the Department of Health should host a high level national training summit. The training summit would bring together commissioners and other relevant agencies from health and social care, and relevant partner organisations, to share best

practice in training and increasing workforce capacity with regard to autism. This would help to ensure that local training plans are developed to a high standard, based on existing good practice.

### Multi-tiered training

Local and national training strategies must be tiered such that they target in-depth, higher level training at staff whose roles most significantly impact upon adults with autism, and lower levels of awareness training at staff whose roles will impact upon adults with autism but less frequently or significantly.

In Appendix 3 the levels of training required by staff in different roles is set out. Appendix 2 also sets out how each of these levels of training would be defined.

### **Summary of recommendations**

- Autism training for key professionals in health, social care and employment services must be included in initial professional training syllabuses
- In particular, professionals involved in social care needs assessments must be suitably trained in autism, and must seek support to carry out assessments when they are not suitably trained
- Psychiatric training must include experience in the diagnosis, assessment and management of individuals with autism, as recommended by the Royal College of Psychiatrists
- A cross-Departmental national training strategy must be developed and delivered to ensure that all staff whose roles impact upon adults with autism are given an appropriate and proportionate level of training. This should be based upon the recommended levels set out in Appendix 3.
- The adult autism strategy should require workforce development plans for public sector professionals to include autism training.
- Autism Coordinators must increase capacity among employers to take on adults with autism and help employers identify suitable positions for people with autism.
- DH must invest in a training scheme to ensure that more professionals gain the skills to diagnose autism in adults, funding training and awareness-raising resources which would be developed and distributed locally, supported by a web-based resource
- Local APGs must develop and deliver a training strategy at a local level to identify skills and knowledge gaps among professionals and commission training appropriately
- DH should host a high level national training summit, bringing together commissioners and other relevant agencies from health and social care, and

relevant partner organisations, to share best practice in training and increasing workforce capacity with regard to autism.

### **Improving awareness and understanding**

Awareness campaigns at all levels will be a necessary part of achieving real social inclusion for adults with autism. Ignorance, prejudice and negative stereotypes remain commonplace in society, and these things remain at the heart of the isolation, social exclusion and unemployment of many adults with autism.

Nationally, the Department of Health must fund a high-profile awareness raising campaign aimed at challenging stereotypes and increasing understanding of autism among the general population.

At a local level, local authorities and PCTs should, via the SAT, take action to raise awareness through events and campaigns, delivered in partnership with adults with autism and their families and relevant voluntary sector and self-advocacy groups. These should be aimed at relevant professionals within the locality, such as those working in health and social care, employment services and employers, police and public transport staff.

We would also recommend that the Home Office and Ministry of Justice encourage police forces, magistrates courts and other local bodies involved in criminal justice to engage with third sector organisations to develop awareness raising initiatives. For instance autism alert cards and other measures have been developed in the West Midlands (case study below).

#### **Case study – Autism West Midlands**

*Autism West Midlands is a regional charity that works with a wide range of individuals with Autistic Spectrum Disorder and their families. The Helpline that they run began to experience a steady increase in calls about criminal justice issues. These were often from parents whose teenagers or young adults had become involved with the criminal justice system in some way, either as a victim, a witness or a perpetrator of a crime.*

*In 2003 this led to the setting up of the ASD and CJS Forum in the West Midlands with representatives from across the criminal justice system and those involved with autism. One of the first actions the forum took was to create an “attention card” that could be carried by people with autism and shown to police officers and other people when they found themselves in a situation that they could not cope with and they were unable to explain about their difficulties. Since 2004, 1293 cards have been issued. The endorsement of the cards by the Police, who agreed to have their logo on each card, has made them a great success.*

#### **Summary of recommendations**

- DH must fund a high-profile awareness raising campaign aimed at challenging stereotypes and increasing understanding of autism among the general population

- Local authorities and PCTs should, via the SAT, take action to raise awareness through events and campaigns, delivered in partnership with adults with autism and their families and relevant voluntary sector and self-advocacy groups
- Home Office and Ministry of Justice should encourage police forces, magistrates' courts and other local bodies involved in criminal justice to engage with third sector organisations to develop awareness raising initiatives.

## **Appendix 1: Summary of all recommendations\***

\*This summary does not include recommendations in the Implementation chapter

<b>Key:</b>	
DH	Department of Health
DWP	Department of Work and Pensions
HO	Home Office
DCLG	Department of Communities and Local Government
DfT	Department for Transport
MoJ	Ministry of Justice
DCSF	Department of Children Schools and Families
ODI	Office for Disability Issues
LAs	local authorities
PCTs	Primary Care Trusts
SHAs	Strategic Health Authorities
<i>(Where the recommendations are locally led, brackets indicate the responsible Department.)</i>	

### **Social inclusion**

<b>Appropriate support and access to services</b>	<b>To be actioned by</b>
A Specialist Autism Team must be established within every local authority / PCT boundary	LAs, PCTs (DH)
All local authority / PCT partnerships appoint a suitably senior member of management staff as responsible for implementing the autism strategy. This member of staff should also be the same as the chair of the Autism Planning Group, and should be a commissioner with responsibilities across health and social care	LAs, PCTs (DH)
The strategy, and the revised guidance on eligibility criteria, must make it clear that determining access to services on the basis of IQ is unacceptable	DH
The forthcoming White Paper on adult social care must address improving outcomes for adults with a learning disability as a priority, and in particular how the funding gap will be addressed for this group	DH
Preventative and 'low level' autism services must be prioritised by commissioners	LAs, PCTs (DH)
DH must commission new research to improve knowledge and understanding around effective interventions for adults with autism	DH
DH must support the development of an autism accreditation service to work with local bodies and support them to meet agreed service standards.	DH
<b>Assessments</b>	
FACS assessments for adults with autism must be carried out by an appropriately autism-trained professional who has a good	LAs (DH)

understanding of the nature of autism in order to assess their needs properly and fairly	
That strategy should make it clear that services should be provided on the basis of need, rather than assumptions about a condition or disability	DH
The Specialist Autism Team should support FACS assessors to carry out care assessments for individuals with complex needs	LAs (DH)
FACS assessments must be complimented by an outcome-focused, person-centred plan	LAs (DH)
<b>Data collection, strategic planning and commissioning</b>	
The Department of Health must continue with plans to conduct a comprehensive national prevalence study, and must consult with stakeholders, including the NAS as part of the tendering process	DH
An Autism Planning Group must be set up, consisting of learning disability and mental health commissioners and managers, representative(s) from the SAT, representatives from the voluntary sector, adults with autism and carers and a representative from children's services. It must be chaired by a senior commissioner who covers both mental health and learning disability services.	LAs, PCTs (DH)
The Autism Planning Group must ensure that existing sources of information are brought together, including SEN data, GP records and local disability databases to gain a better understanding of the local autism population	LAs, PCTs (DH)
The Autism Planning Group must take proactive steps to identify adults with autism currently unknown to services, with support from the Government Offices and the Department of Health	LAs, PCTs (DH)
The Department of Health must work with best practice local authorities and trial local schemes in order to develop models to improve local authorities' data collection and record keeping of people with autism	DH, LAs
The chairs from local Autism Planning Groups must convene at a regional level to share information and best practice, and to commission strategically at a regional level where appropriate	LAs, PCTs (DH)
Local authorities must carry out their existing duty to maintain disability databases and must ensure that these databases can identify people by type of disability, including autism	LAs (DH)
The strategy must put a specific statutory requirement on local authority / PCT partnerships to include the needs of adults with autism in their Joint Strategic Needs Assessments	LAs, PCTs (DH)
The Public Health Observatory's investigation into improving data collection and sharing on adults with learning disabilities among GPs must be extended to include information on adults with autism across the spectrum, not just those with a learning disability	DH
Screening tools should be used in prisons to identify adults with autism	DH, HO
The PANSI data-source and outcomes of the national prevalence research must be added to the JSNA core dataset	DH
The good practice guidance on JSNAs, due to be published this year, must explicitly and thoroughly address the issue of autism and how best to ensure that the needs of adults with autism are reflected in the JSNA	DH

process	
The Government must follow through with the commitment to produce world class guidance to improve strategic commissioning for adults with autism.	DH
<b>Housing and support</b>	
The Autism Planning Group must ensure that suitable residential or supported living arrangements are available locally for adults with autism	LAs, PCTs (DH)
Commissioners must be autism-trained to ensure that they commission appropriate support for adults with autism	LAs, PCTs (DH)
The Department of Health must extend its work with the Department of Communities and Local Government to ensure that mainstream housing policies are inclusive of all adults with autism, including those who do not have an accompanying learning disability	DH, DCLG
Local authorities must give the specific needs of adults with autism full consideration when developing housing plans, including environmental and sensory issues, through consultation with adults with autism and their families	LAs (DH)
Local authorities should review the support offered by their Supporting People services with a view to ensuring that appropriate housing support is available or adults with autism	LAs (DH)
The Department of Health must work with the Department of Communities and Local Government to develop guidance on the accessibility requirements of housing for adults with autism	DH, DCLG
<b>Transport</b>	
The specific transport needs of adults with autism must be given full consideration in FACS assessments and person-centre plans	LAs (DH)
The Autism Planning Group must ensure that travel training for adults with autism is available locally	LAs, PCTs (DH)
Adults with autism must be involved in local decision-making processes about transport	LAs (DfT)
The Department for Transport, working with the Department of Health, should produce guidance on making transport accessible for people with autism	DfT, DH
Department of Transport should make it clear to the bodies that issue these passes that adults with autism are entitled to disability bus concessions	DfT
The national concessionary bus pass scheme must be amended such that free companion bus passes must be issued to adults with autism who need a companion in order to use a bus safely	DfT
Blue Badge eligibility for people with autism and their families must be determined according to need, not by medical definition or ability to walk	DfT
Clear guidance about the transport needs of people with autism must be issued to medical practitioners carrying out Blue Badge assessments	DfT, DH

## Health

<b>Diagnosis and post-diagnostic support</b>	<b>To be actioned by</b>
DH must ensure that adult diagnostic services are available at a local level	DH
The SAT must include at least one member of staff (a clinical psychologist/psychiatrist or equivalent) who is qualified to diagnose adults with autism	PCTs (DH)
Diagnosis must be a multi-disciplinary process, involving a range of different professionals	PCTs (DH)
Regional specialist services for autism must be established at Strategic Health Authority level	SHAs (DH)
The Government must invest in a training programme to increase the number of clinicians who are qualified to diagnose autism	DH
The remit of the NICE guidance on diagnosing autism in children must be extended to include diagnosis of adults	DH
Comprehensive post-diagnostic support must be provided by the SAT as part of the diagnostic process	PCTs, LAs (DH)
SATs must develop comprehensive, transparent referral pathways for diagnosis and support	PCTs, LAs (DH)
Sufficient training must be given to all frontline healthcare professionals such that they are able to recognise signs of autism as part of the referral pathway	DH
<b>Access to primary healthcare</b>	
The annual health checks initiative currently being rolled out to adults with learning disabilities must be extended to include adults with autism who do not have a learning disability	DH
The Department of Health must develop guidance for healthcare providers to make healthcare more accessible to people with autism, taking sensory needs fully into account	DH
The strategy should reiterate to healthcare providers their duty under the Disability Discrimination Act to consult adults with autism on all elements of their service, including ensuring that the setting is accessible	DH
Autism training must be incorporated into the initial professional training syllabus and workplace development plans for GPs, mental health professionals and other NHS staff	DH
PCT programmes such as IAPT must be made available to adults with autism and comorbid mental health problems, and professionals administering IAPT must be specifically trained to make the necessary adjustments for patients with autism	PCTs (DH)
Inpatient mental health wards must be made accessible and safe for adults with autism, through ensuring suitability of environment and training staff. DH should issue guidance to inpatient wards to facilitate this.	DH

## Choice and control

<b>Personalisation</b>	<b>To be actioned by</b>
The 'trailblazers' for Right to Control, as well as the pilots for personal health budgets, must ensure that outcomes for adults with autism are able to be evaluated as a distinct category	ODI
The Department of Health must issue new guidance on Resource Allocation Systems to emphasise that they are only intended to be used to provide an indicative budget, and that they are to be followed up with a more comprehensive assessment of need. The Department of Health must also support the distribution of the <i>Putting Everyone First</i> document	DH
Local authorities must ensure that resource allocation for individual/personal budgets and direct payments, however it is determined, takes into account the additional costs associated with specialist autism support. Budgets must also cover the costs of necessary brokerage and advocacy	LAs (DH)
There must be a national debate on the principles underpinning resource allocation as called for in the Evaluation of the Individual Budgets Pilot	DH
The SAT must be accountable for ensuring that autism-appropriate support brokerage is available locally, in conjunction with the voluntary sector where appropriate	LAs, PCTs (DH)
The APG must ensure that appropriate services are commissioned locally to reflect the support that individuals wish to buy with their personal/individual budgets and direct payments	LAs, PCTs (DH)
Individuals must be given a clear choice, based on accessible information, as to how they would like to receive their care (i.e. through direct payments, individual budgets or direct from the local authority)	LAs (DH)
Local training plans must ensure that all employers, including the local authority itself, individuals accessing support and local care agencies, can access training for their employees	LAs (DH)
Safeguarding Boards must support people who pay for services through direct payments	Safeguarding Boards (DH, HO)
Measures must be developed to help enable people to develop robust circles of support in order to combat financial or other abuse that may occur in purchasing services through direct payments or personal/individual budgets.	Safeguarding Boards (DH)
All adults with autism who are eligible for support must have access to, and be offered, a person-centred plan.	LAs (DH)
<b>Transition</b>	
Local authorities must be reminded of their existing duties around transition, including starting transition plans at age 14, and basing them on the aspirations of the young person. They must include a strong employment focus and be carried out by staff trained in autism	LAs (DH)

Young people with autism must be provided with transition support leads, like those introduced to support young people with learning disabilities.	DH
Statutory duties around transition must be extended to include all children who are supported through School Action Plus.	DH, DCSF
CAMHS must be required to carry out transition planning for children using their services. Where children are unlikely to meet referral criteria for an adult mental health team, measures should be put in place to support them through alternative services.	CAMHS (DH, DCSF)
At least one person from children's services must attend Autism Planning Group meetings to ensure that gaps in provision for children currently going through transition are identified and commissioned.	LAs, PCTs (DH)
Directors of Children's Services must be given a duty to maintain an accurate database of the numbers of children with autism in the local area, which must be shared with the Director of Adult Services and the APG to ensure effective service development.	DCSF, LAs, PCTs (DH, DCSF)
The specific difficulties faced by adults with autism with regard to transitions that occur during adulthood must be recognised in person-centred plans, with appropriate support put in place.	
<b>Advocacy</b>	
Advocacy must be made available to all adults with autism and must be free for the individual to access.	LAs (DH)
All advocates expected to work with people with autism must be appropriately autism trained. The national qualification on advocacy must cover autism and the communication needs of people with autism.	LAs (DH)
The SAT should support the development of local advocacy and self-advocacy groups	LAs (DH)
<b>Involvement and participation of adults with autism</b>	
The strategy must emphasise the need for public bodies to specifically involve people with autism, their families and carers, in meeting their responsibilities under the DED. Any consultation documents or events must be fully accessible to people with autism.	DH
The Department of Health retain the strategy External Reference Group to monitor implementation of the strategy and act as an advisory board.	DH

## Access to training and employment

Access to the benefits system	To be actioned by
The Department for Work and Pensions must take action to improve awareness of entitlement to benefits among adults with autism	DWP
Staff involved in the benefit application process must be sufficiently trained to communicate with adults with autism	DWP
Everyone applying for ESA must be informed of their right to an advocate and for those who want an independent advocate they must be supported to access one	Jobcentre Plus (DWP)
Sick notes for ESA should be scrapped	Jobcentre Plus (DWP)
Atos doctors must be sufficiently trained in autism to carry out Work Capability Assessments	DWP
Professor Paul Gregg's recommendation that the first sanction for benefit claimants be replaced by a written warning should be implemented straight away	Jobcentre Plus (DWP)
All written communications that concern sanctions or meetings at Jobcentre Plus to be automatically provided in easy read and plain English formats	Jobcentre Plus (DWP)
Working age DLA forms must be revised to recognise the care and mobility needs of people with autism. The DLA checklist must be abolished	Pension Disability and Carers Service (DWP)
Preparing for and finding work	
Connexions should ensure that transition plans for young people with autism have an employment focus, including seeking opportunities for work experience.	Connexions (DCSF)
All existing DEAs who did not receive autism training on starting the job should be given the new training as a priority	Jobcentre Plus (DWP)
Personal Advisers within Jobcentre Plus must be autism trained	Jobcentre Plus (DWP)
Autism Coordinators must be introduced to Jobcentres to ensure that there is a clear source of autism information and advice available to all Jobcentre Plus staff, to increase awareness of autism among local employers and to join up existing autism services within an area.	Jobcentre Plus (DWP)
SATs must have an employment focus to ensure that people with autism are given the right support to find employment.	LAs, PCTs (DH, DWP)
Data must be collected and analysed annually on outcomes for adults with autism using Pathways to Work and Workstep / Work Preparation (soon to become Work Choice).	DWP
The Department for Work and Pensions must make sure that contracts for Work Choice include specific requirements for supporting adults with autism.	DWP
Ofsted inspections must identify how well provision works for adults with autism.	Ofsted

<b>Supporting adults with autism in employment</b>	
Access to Work assessors must be given appropriate levels of autism training	DWP
Access to Work publicity must stress to employers that the scheme can help with non-physical adaptations and support.	DWP
The Department for Work and Pensions must issue guidance as to the reasonable adjustments employers can make for people with autism. Autism Coordinators have a key role to play in raising awareness of autism among, and developing relationships with, local employers.	DWP
The Department of Health must set targets for Government Departments to employ people with autism.	DH
DH must act on the commitment to the Public Accounts Committee to be an exemplar in employing adults with autism.	DH
<b>Access to further education</b>	
The Autism Planning Group should include within its remit the need to ensure that appropriate further education courses are available locally	LAs, PCTs (DH)
Further education curricula must include the teaching and training of independent living skills for students with autism	LAs (DCSF)
Staff working at post-16 education providers should be trained to appropriate levels (see appendix 3)	LAs (DCSF)

## Awareness raising and training

<b>Training needs of key professionals</b>	<b>To be actioned by</b>
Autism training for key professionals in health, social care and employment services must be included in initial professional training syllabuses	DH, DWP
In particular, professionals involved in social care needs assessments must be suitably trained in autism, and must seek support to carry out assessments when they are not suitably trained	DH
Psychiatric training must include experience in the diagnosis, assessment and management of individuals with autism, as recommended by the Royal College of Psychiatrists	DH
A cross-Departmental national training strategy must be developed and delivered to ensure that all staff whose roles impact upon adults with autism are given an appropriate and proportionate level of training. This should be based upon the recommended levels set out in Appendix 3.	All Government Departments
The adult autism strategy should require workforce development plans for public sector professionals to include autism training.	DH
Autism Coordinators must increase capacity among employers to take on adults with autism and help employers identify suitable positions for people with autism.	Jobcentre Plus (DWP)
DH must invest in a training scheme to ensure that more professionals gain the skills to diagnose autism in adults, funding training and awareness-raising resources which would be developed and distributed locally, supported by a web-based resource	DH
Local APGs must develop and deliver a training strategy at a local level to identify skills and knowledge gaps among professionals and commission training appropriately	LAs, PCTs (DH)
DH should host a high level national training summit, bringing together commissioners and other relevant agencies from health and social care, and relevant partner organisations, to share best practice in training and increasing workforce capacity with regard to autism.	DH
<b>Improving awareness and understanding</b>	
DH must fund a high-profile awareness raising campaign aimed at challenging stereotypes and increasing understanding of autism among the general population	DH
Local authorities and PCTs should, via the SAT, take action to raise awareness through events and campaigns, delivered in partnership with adults with autism and their families and relevant voluntary sector and self-advocacy groups	LAs, PCTs (DH)
Home Office and Ministry of Justice should encourage police forces, magistrates courts and other local bodies involved in criminal justice to engage with third sector organisations to develop awareness raising initiatives.	HO, MoJ

## **Appendix 2: Indicative training level outlines**

### **Autism Awareness training**

#### Outline of content

- 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

#### Possible means of delivery

- Short DVD followed by discussion
- Leaflets to be developed and distributed
- A website should be developed as a one-stop shop for basic autism awareness

#### Comments

- A web-based resource will be necessary because of the potentially huge demand.
- Content will need to be agreed in consultation with people with autism, families and professionals to ensure quality control.

### **Tier 1: Induction**

#### Outline of content

- Content in Autism Awareness training built upon, expanding on key points
- Historical context of autism
- Ethics, values and inclusive practice
- Introduction to the key principles of intervention and individualised practice
- Impact on individuals and families.

#### Possible means of delivery

- One day / half day course, including instruction and discussion, and group and individual work, for example SPELL induction or Autism Focus.

#### Comments

- As above, content will need to be agreed in consultation with people with autism, families and professionals to ensure quality control, and guided to meet agreed criteria.
- Much of the content already exists, but capacity to deliver will need to be built.
- Training will need to be audited to ensure quality and consistency

- Training can be built into Continuing Professional Development (CPD) skills frameworks

## **2. Intermediate**

### Outline of content

- Builds further on above
- Focus on the practical application of principles
- Detailed content on ethics and safeguards
- Different methods of intervention and models of services covered

### Possible means of delivery

- Delivered using the CPD model
- A series of workshops would be agreed, covering theory and practice
- Established frameworks could be used, e.g. TEACCH / SPELL 1 and 3 (NAS and Tizard Centre)

### Comments

- All comments for induction training also apply here (see above)
- Formal evaluation / accreditation of training will be necessary at this level.
- CPD credits should be gained in completing this training

## **3. Advanced**

### Outline of content

- Application of theory at more advanced level
- Research and/or evidence based practice
- Analysis of behaviours and interventions
- Refreshment of practice – challenging prevailing ideas and concepts

### Possible means of delivery

- Delivered using the CPD model, building on previous model
- Delivered by expert trainers to ensure a consistent message.
- Certified level courses, e.g. B'ham University, could be utilised

### Comments

- Quality control through formal evaluation and accreditation of courses and learning.
- CPD credits should be gained in completing this training
- Again, capacity to deliver needs to be built, but much of the content already exists.

## 4. Specialist

### Outline of content

- Leading interventions and practice in diagnosis, assessment and intervention
- Specialist behavioural or psychopharmacological interventions

### Possible means of delivery

- Access to specialist training in key areas, such as:
  - ADOS
  - ADI
  - DISCO
  - Dunn profile
  - other psychometrics
  - assessment TRIAD
  - RAMAS

### Comments

- Accredited training and instruments and formal controls essential
- Capacity already exists but may need refinement.

### Appendix 3: Training Requirements

E = Essential

D = Desirable

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			

	16. Reception staff at GP surgeries/other healthcare settings		E				
<b>2. Social care</b>	17. Agency wide	Provision of social care and support services	E	E	E	E	E
	18. Partnership boards	Strategy and services	E	E	E	D	
	19. Social worker	Assessment Support	E	E	E	D	D (E) if assessment
	20. Senior manager	Allocation of resources	E	E	D		
	21. Care manager	Placement and services	E	E	D		
	22. Support worker	Support in services	E	E	E	D	D
	23. Service manager	Registered manager	E	E	E	E	E

	24. Befriender	Informal befriending	E	E	D		
	25. Community teams	Support for individuals	E	E	D		
	26. Mentor		E	E	D	D	E
	27. Personal assistant	Home support	E	E	E	D	
	28. Administrator (e.g. contracts)		D				
<b>3. Criminal justice and related</b>	29. Agency wide Dept of justice and Home Office	Administration of justice	E	E	E	E	E
	30. Police force	Victim support Crime prevention Investigation Prosecution	E	E	D	D	
	31. Senior police officers		E	D	D		

	32. Police officers	On street contact Victim support	E	D			
	33. Appropriate adult	Protection and support Victim support	E	E	D	D	
	34. Custody sergeant	reception	E	E	D		
	35. CPS	Decisions on prosecution	E	D			
	36. Magistrates and judiciary		E	D			
	37. Probation staff	Pre trial and aftercare support	E	E	D		
	38. Courts staff	Conduct of the court	E				
	39. Senior prison staff		E	D			
	40. Personal officers (prison)		E	E	D		
	41. Prison officers		E	D			

	42. Secure hospital staff	Nursing and associated	E	E	D		
	43. Prison / secure hospital therapists	e.g. CBT Anger mnmt etc	E	E	E	D	E e.g. if CBT or group interventions
	44. Prison/ secure hospital healthcare staff		E	E	D	D	
	45. Prison / secure hospital Psychology		E	E	E	D	
	46. Prison/ Secure hospital social worker	In reach and aftercare	E	E	E	D	
	47. Prison / secure hospital vocational staff		E	D	D		
	48. Forensic Psychiatrists	Specialist diagnosis assessment and support	E	E	E	E	E
	49. Police / secure hospital medical officer		E	E	D		
	50. Solicitors	advocacy	E	D			

	51. Barristers	advocacy	E	D			
	52. Hostel staff		E	E	D		
	53. Prison religious	e.g. chaplain imam, priest	E	D			
	54. Parole boards		D				
<b>4. Statutory Inspectorate</b>	55. OFSTED 56. CQC	Inspectorate	E	E	E	E	
	57. Inspector	Inspection	E	E	E	D	
<b>5. Education</b>	58. Continuing education	Higher and continuing education and training	E	E	D	D	
	59. Senior staff and management		E	D			
	60. Lecturer	tutor	E	E	D	D	
	61. Counselor	mentoring	E	E	E	D	E

	62. Student welfare officer	Student welfare	E	E	D	D	D
	63. Secondary education	Teachers, teaching support staff, others involved in transition	E	E	D	D	

<b>6. Benefits Employment, and vocational</b>	64. Agency wide	Benefits Employment and related services					
	65. Benefits agency staff	Entitlement and adjudication on eligibility e.g. DLA etc	E	D E if assessor	D E if assessor	D	
	66. Job centre staff		E	D E (if assessor)	D E (if assessor)		
	67. DEA		E	E	D		
	68. Manager job centre		E	E	D		
	69. Connexions staff		E	E	D		

	70. Employers of people with ASD		E	D	D		
	71. Specialist emp. Agencies	Work for people with ASD	E	E	E	D	E
Day service staff	72. Vocational and occupational	E	E	E	D	D	Day service staff
<b>7. Emergency services</b>	73. Police 74. Fire Service 75. Ambulance	Emergency response	D				
<b>8. MISC.</b>	76. Advocates	Citizen advocacy	E	E	E	D	D
	77. Leisure services and retail		D	D			
	78. Financial institutions		D				
	79. Social group leader		E	E	D	D	
	80. Volunteer coordinator		E	E	D	D	

	81. Relevant politicians	Elected members of LA e.g. relevant committees	D	D			
	82. Citizens advice staff		D				
	83. Samaritans	Emergency counseling	E	D			
	84. Marriage Guidance Counselors		E	D			

## A better future

NAS Prospects response

September 2009

### **About us**

Prospects is the National Autistic Society's employment and training service for people with autism. We work to ensure that people with autism have the same training and employment opportunities as non-disabled people.

#### *Preparing for work*

Prospects offers work preparation programmes, job-finding support, interview support and employment support to people with autism.

#### *Support for employers*

Prospects helps employers with the recruitment, training and retention of staff with autism. Our employment consultants provide advice, support and training to managers and their teams.

#### *Student and graduate support*

Prospects supports students and graduates with autism.

### **Autism and work**

There are many different barriers facing people with autism (including Asperger syndrome) trying to find work:

- Lack of awareness or understanding of autism among employers.
- Lack of access to specialist support during the application and recruitment process, including interview support.
- Employers not understanding the reasonable adjustments that can be made to the recruitment process for people with autism and why these are needed. For example, not realising that it is a reasonable adjustment to allow someone to be accompanied by an Employment Support Worker to assist with their interview.
- Recruitment methods that are inappropriate for people with autism, such as telephone interviews and group interviews.
- Job specifications which stipulate that the candidate must have "good communication skills", even for jobs where these are not required or could be adjusted, in accordance with the Disability Discrimination Act, to meet an individual's particular needs.

### **Starting early**

Young people with autism need to be given the opportunity to undertake work experience placements on the same basis as their non-disabled peers. Work experience enables individuals to experience both the world of work and a specific work environment that interests them. Work experience is a valuable learning experience that helps with the student's pathway from school into further education and employment and teaches them valuable and useful skills that they can apply in other aspects of their education and personal lives.

### **Work experience programme**

With funding from the National Transition Support Team, Prospects is running a work experience programme with the Sybil Elgar School in West London. Sybil Elgar is an NAS school for children and young people with autism.

The first stage of the project ran from June- July 2009 for five weeks, with one workshop a week. It ran with six students from Sybil Elgar who are looking for work experience placements in the 2009/2010 academic year. The workshops were all themed and each one focused on a specific area around work experience, such as choosing the right placement, communicating with others and working with others.

The second stage of the project will run September 2009 to November 2009. This will involve a final workshop and then the students will attend their placements from late September. The placements will be supported by both staff at Prospects and staff at the school. Prospects will also support and train the companies that take on the students in regards to disability awareness and how to make positive adjustments to support the students.

- Connexions should ensure that transition plans for young people with autism have an employment focus, including seeking opportunities for work experience.

### **The importance of autism-specific support to find work**

Only 15% of people with autism are in full time paid employment.<sup>1</sup> Specialist autism employment support makes a real difference in helping people with autism move into work, and research has shown that Prospects has a success rate of 68%.<sup>2</sup>

### **The journey to work**

Tomas has a diagnosis of Asperger syndrome and started at Prospects in February 2007. Tomas had been unemployed for 2 years.

Tomas had very realistic career goals and was determined to achieve paid employment. His difficulties included communicating effectively at work, time management, and understanding instructions. He also found the recruitment process very difficult.

During his time at Prospects, Tomas attended group and 1:1 sessions covering the areas he found difficult. His time management improved hugely, as did his confidence. He completed a six week work experience placement at WH Smith's which gave him the opportunity to develop skills in a busy retail environment. His feedback from this placement was excellent, which in turn helped to build his confidence in preparation for job searching.

Tomas attended every jobfinding session at Prospects and took his group and individual preparation sessions very seriously; he became notably more competent at completing application forms and attending interviews. Tomas also did a great deal of independent job searching - he regularly handed in his CV to different stores across London, something he had found difficult in the past.

<sup>1</sup> Rosenblatt, M. (2008) I Exist, NAS

<sup>2</sup> Howlin P, Alcock J, Burkin C, 'An 8 year follow-up of a specialist support employment service for high-ability adults with autism or Asperger syndrome' in *Autism* 9(5) (2005).

Eventually Tomas secured a permanent full-time position as a stock assistant at Habitat. Tomas quickly became a dedicated and hard-working member of the team; he learned how to store and arrange stock, and became friends with his two closest colleagues. His managers were given information regarding the support and management of staff with Asperger syndrome.

Tomas' experience shows what a difference autism-specific employment support can make. However, this support is currently only available in a few areas and Government contracts make it increasingly difficult for specialist providers like Prospects to engage in schemes like Pathways to Work and Flexible New Deal.

As the majority of jobseekers with autism are further from the workplace than other disadvantaged jobseekers<sup>3</sup>, it is more costly to provide the right support, yet contracts currently fail to recognise this. As prime providers for Pathways to Work and other Government programmes seek to subcontract to specialist organisations, like Prospects, they are offering a sum that fails to recognise the additional costs involved in supporting clients with more complex needs.

- The Department for Work and Pensions must make sure that contracts for Work Choice include specific requirements for supporting adults with autism.
- Ofsted inspections must identify how well provision works for adults with autism.

It is also important that the Government looks into ways of improving autism expertise among Jobcentre Plus staff and other providers of employment support. Prospects has recently developed an innovative partnership with Remploy, which will involve Prospects delivering autism-specific training to Remploy staff, ensuring that there is good autism awareness throughout the staff team in each Remploy branch.

- Autism Coordinators must be introduced to Jobcentres to ensure that there is a clear source of autism information and advice available to all Jobcentre Plus staff, to increase awareness of autism among local employers and to join up existing autism services within an area.

## **Voluntary Work**

Autism is a spectrum condition and everyone is different. However, all people with autism should be given the opportunity to work in either paid, or voluntary, roles according to their needs and circumstances. All work provides a way to engage with society and develop social and communication skills and everyone has a right to experience this. Furthermore, for some, voluntary work can also serve as a route to paid employment.

### **The right support**

In January 2008 David, who has Asperger Syndrome, started Prospects' Brighter Horizons course. This course is designed to develop work-related skills and to support individuals to find and undertake an extended voluntary placement.

David attended weekly group workshops on various subjects such as coping at work, facing the future, workplace relationships, and healthy living. He also attended one-to-one

<sup>3</sup> As recognised by the DWP, in its extension of Prospects London's Work Preparation programme to a 20-week course for jobseekers rather than the usual 13 weeks.

sessions every week where he focused on areas that he felt he needed to improve in, for example David has always struggled to make friends: something that he finds particularly difficult is starting and ending conversations, and knowing what to say when he first meets someone. In his one-to-one sessions he spent a lot of time discussing conversation skills and how to interpret body language. He also focused a lot on appropriate and inappropriate topics of conversation at work and began to search for a suitable voluntary placement.

David was keen to work in a supermarket and his employment support worker found him an eight-week placement as a grocery assistant at a local supermarket. David started his placement in April 2008. The work involved replenishing the stock in various departments, collecting stock from the warehouse and helping customers with their shopping. He worked 3 days per week for 5 hours per day. His employment support worker visited David weekly to discuss with him how everything was going and talk about any problems that had occurred. His employment support worker would also meet with David's supervisor to discuss any issues that had arisen. His colleagues were very supportive and friendly, and David was receiving extremely positive feedback on the work that he was doing.

As the placement progressed David's confidence increased and he made it clear that he was thoroughly enjoying his new role. David said that he liked working there because it felt good keeping busy and gave him a sense of responsibility.

On the last day of David's placement his employment support worker met with David's supervisor. He said that David had actually been working harder than most of the full-time employees and asked David if he would like to join the team as a paid employee when a role became available.

### **Support for employers**

The effectiveness of Access to Work for people with autism varies across England, with people really struggling to access appropriate support for their autism through the scheme in some areas. There needs to be consistent provision across England and guidance needs to be issued making clear how Access to Work can be used for non-physical disabilities and specifically autism.

- Access to Work assessors must be given appropriate levels of autism training.
- Access to Work publicity must stress to employers that the scheme can help with non-physical adaptations and support.