The NAS believes the Commission should recommend

- Greater investment in the social care system to take into account the needs of people with a lifelong condition who cannot pay for their care. If people are economically disadvantaged, because of their caring role or their disability, the future funding system must take this into account
- A real focus on preventative and lower level services, including social programmes and social skills training for adults and children with autism, which can prevent people with autism going into crisis and save significant amounts of money in medium to long term
- Money is made available – paid for through joint health and social care budgets – for specialist autism teams. We would also encourage the Commissioners to visit a specialist team to see at first hand the work they do
- Funding is provided to local authorities and the NHS to implement the adult autism strategy and statutory guidance in full
- The DWP allocate money to local authorities to fund autism-specific support, including social skills and self-advocacy training, which will provide both social care and support employability. This would be similar to the £1 billion transfer of NHS funding to social care in consideration of the health benefits which will accrue, announced by DH in October 2010
- Work is done to ensure that the benefits of personalisation are realised for people with autism and money is spent on brokerage schemes like the one currently operating in Bury.
Introduction
The NAS warmly welcomes the opportunity to comment on the future funding of adult social care. We agree with the Commission that fair funding should be a priority, and welcome a focus on getting to the heart of how money is spent and ensuring that value for money is being achieved. In doing this, the NAS recommends that the recent National Audit Office study into public spending on adults with autism is given due consideration.

The NAS does not believe that there is enough state funding available in the short term to achieve the best value for money (lowest overall cost) in the medium to longer term. A fair funding system must mean that we are being fair in the way that we allocate state funding to social care. There needs to be a proper focus on preventative services and lower intensity supports that can stop needs escalating and actually save money in the long run. We must, think about how we can fund care as a whole, including funding the care and support received by those people who cannot afford to contribute anything.

About us
The National Autistic Society (NAS) is the UK’s leading charity for people affected by autism.1 We were founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. Today we have 20,000 members, 100 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.

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.

1 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 and recent figures from the NHS Information Centre have confirmed a similar prevalence figure among adults. By applying the 1 in 100 figure we estimate that over 415,000 people in England have autism. Together with their families, they make up over one million people whose lives are touched by autism every single day.

Unfortunately, we know that people with autism routinely struggle to access the services they need and consequently outcomes are poor:

• Over 60% of adults with autism rely on their families for financial support and 40% live at home with their parents
• 63% of adults with autism report that they do not have enough support to meet their needs
• As a result of this lack of support, a third of adults with autism have developed a serious mental health problem
• Just 15% of adults with autism are in full-time employment
• 71% of children with autism have a co-occurring mental health condition

Health, social care and autism
In 2008 the NAS launched the I Exist campaign. As part of this campaign we surveyed 1,400 people in England with autism and their families as well as local authorities and PCTs. A large part of this research looked at the experiences of people with autism in accessing social care and of the services they received. To our knowledge, this is largest survey of its kind.

The report revealed a number of key barriers that prevented adults with autism from accessing the services they needed, most notably the structure of local services and the lack of local data on adults with autism needed to help plan and commission services.

Over 60% of adults with Asperger syndrome or high functioning autism who responded to the survey said 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. The issue of

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3 All the above information is taken from the NAS I Exist report. For more information please visit http://www.autism.org.uk/iexist.


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.\(^6\) This explains in part why many people with autism are unable to access health services.

This problem is compounded by the lack of adequate data. Good data is not only essential, it is urgently needed and the lack of data is particularly detrimental to the commissioning process. It is the Government’s vision that the Joint Strategic Needs Assessment (JSNA) acts as the primary source by which both health and social care services are to be commissioned. However, at present, there are no references to autism prevalence in any of the statistical sources included in the JSNA core dataset that is supposed to support local authorities and PCTs to source appropriate local information. Indeed, just 20% JSNAs even mention autism, let alone ensuring services are planned through this process.\(^7\)

In our opinion, one of the best ways to resolve the structural and data problem is to establish a specialist autism team within every local authority or emerging GP Consortia, supported and overseen by an autism planning group or partnership board. The adult autism strategy for England, published in April 2010, recognised that where things were working well in a local area this was often as a result of the development of such a team. It recommended that local services look at the models of teams that have been developed and consider developing one locally. In Appendix A we have set out what we believe are the core roles of a specialist autism team. **Although we would urge the Commissioners to visit a specialist team to see at first hand the work they do.**

To summarise, however, their role is to build capacity within mainstream service. This would be achieved through staff training and support, to assist with care assessments in complex cases and to provide and/or signpost towards low-level autism-specific services for those who are falling through the gaps. The specialist autism team would also help existing services provide appropriate support to adults with autism, while simultaneously helping those adults to access those services. It would also act as the primary diagnostic service in an area.

As Figure 1 shows the care pathway for adults with Asperger syndrome and high functioning autism not known to services is a difficult one to steer. All too often people are let down at the first stage (identification) and never reach the third stage (support). Without a local team, it is extremely difficult to build that capacity at a local level or to ensure sufficient autism expertise is available locally.

Further to this, as the care pathway in Appendix B shows, specialist teams instead of acting as the one stop shop for all people with autism are there to interact with the broad range of services and build capacity within the local area and directly support only the most complex of cases, which cannot be picked up by other services.

\(^6\) Ibid.
Figure 1: Care pathway and service utilisation with no specialist service in place

Cost of specialist teams
As part of their work examining the economic cost of autism – which will be discussed later on in more detail – the NAO produced tables detailing how much specialist autism teams cost (see figure 2).

Using this table, we can estimate that annually the cost of running specialist teams in 150 local authorities would cost approximately £24.6m (Kingston cost) or £55.4m (Liverpool cost). Although clearly the NAS realise the financial constraints put on local authorities and the changing political environment, we firmly believe that these teams offer value for money and are cost effective, not least considering the cost of autism on social care that are otherwise incurred.

If we take just one example, as you rightly point out in your consultation document, around 60% of state social care spending on the working-age population is on those with learning disabilities. It has been estimated that between 20% and 33% of adults with learning disability

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8 Excluding Isle of Scilly and City of London.
who receive community care have autism. \(^9\) Across England, this suggests that between 35,000 and 58,000 adults who are likely users of social care services have both learning disabilities and autism (out of a population of 142,000). In 2009/10, learning disability services cost (net) £3.7bn (including supporting people money). This equates to an estimated spend in 2009/10 of £698m or £1.51bn on adults with learning disability services and autism. \(^10\) Specialist teams would help make sure money spent on these services was spent effectively on, for instance, ensuring staff were adequately trained in making reasonable adjustments for people with autism.

Figure 2: Staff mix and costs of existing specialist Asperger services

<table>
<thead>
<tr>
<th>2007 working-age (16-59/64) adult population (000)</th>
<th>Liverpool</th>
<th>Kingston</th>
<th>Northamptonshire(^1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant Psychiatrist</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>0.80</td>
<td>0.50</td>
<td>2.00</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>0.00</td>
<td>0.20</td>
<td>1.00</td>
</tr>
<tr>
<td>Community Psychiatric Nurse/Social Worker</td>
<td>3.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Support Worker</td>
<td>3.00</td>
<td>1.20</td>
<td>0.00</td>
</tr>
<tr>
<td>Admin/Secretary</td>
<td>1.00</td>
<td>0.20</td>
<td>0.30</td>
</tr>
<tr>
<td>Team Manager</td>
<td>0.50</td>
<td>0.40</td>
<td>0.00</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>0.50</td>
<td>0.20</td>
<td>0.00</td>
</tr>
<tr>
<td>Estimated Cost (£)</td>
<td>369,421</td>
<td>163,713</td>
<td>240,073</td>
</tr>
<tr>
<td>Estimated cost per 1,000 of working-age (16-59/64) adult population (£)</td>
<td>1,298</td>
<td>1,536</td>
<td>564</td>
</tr>
</tbody>
</table>

Source: National Audit Office analysis of C&G population estimates, individual service specifications and discussion with service providers. Costs are taken from Curtis, L., Unit Costs of Health and Social Care (Canterbury: Personal Social Services Research Unit, 2008), and where relevant include costs of qualification and autism-specific further training mainstreamed over the individual’s working life.

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

Finally on this point, it should also be noted that although we believe the work of the Liverpool Asperger Team and the Bristol Autism Spectrum Service\(^11\) represent best practice, the NAS would welcome independent analysis of these services to determine the ideal make-up. Nonetheless, Figure 3 shows the potential cost of individual staff members and office expenses per year.


\(^10\) Clearly, the NAS would consider this a minimum baseline figure, because often the services used by adults with a learning disability and autism are often expensive specialist services.

\(^11\) This service was not part of the NAO analysis.
Figure 3: Unit costs assumed for individual team members in specialist Asperger services

<table>
<thead>
<tr>
<th></th>
<th>Consultant Psychiatrist</th>
<th>Clinical Psychologist</th>
<th>Occupational Therapist</th>
<th>CPN / Social Worker</th>
<th>Speech and Language Therapist</th>
<th>Support Worker</th>
<th>Team Manager</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary</td>
<td>117,450</td>
<td>34,300</td>
<td>22,900</td>
<td>28,494</td>
<td>22,900</td>
<td>21,296</td>
<td>35,410</td>
</tr>
<tr>
<td>On costs</td>
<td>29,686</td>
<td>7,422</td>
<td>4,788</td>
<td>7,135</td>
<td>4,788</td>
<td>5,211</td>
<td>9,010</td>
</tr>
<tr>
<td>Qualifications</td>
<td>31,475</td>
<td>22,000</td>
<td>4,171</td>
<td>5,862</td>
<td>4,379</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional training</td>
<td>2,227</td>
<td>113</td>
<td>90</td>
<td>90</td>
<td>115</td>
<td>90</td>
<td></td>
</tr>
<tr>
<td>Overheads</td>
<td>7,904</td>
<td>5,047</td>
<td>4,345</td>
<td>5,344</td>
<td>4,345</td>
<td>3,134</td>
<td>6,663</td>
</tr>
<tr>
<td>Capital Overheads</td>
<td>4,944</td>
<td>2,573</td>
<td>2,972</td>
<td>2,586</td>
<td>2,972</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>193,686</td>
<td>71,455</td>
<td>39,266</td>
<td>49,493</td>
<td>39,499</td>
<td>29,731</td>
<td>53,651</td>
</tr>
</tbody>
</table>

Source: National Audit Office analysis of unit cost data

NOTES
1. Salaries, on-costs and qualification costs are taken from Curtis I, Unit Costs of Health and Social Care (Canterbury: Personal Social Services Research Unit, 2008).
2. No qualification costs are available for clinical psychologists (see Curtis, p.97). Therefore for the purposes of analysis we have assumed an approximate cost of £22,000 (70 per cent of the equivalent cost for a Consultant Psychiatrist). We have explored the possible impact of variations in costs through sensitivity analyses (see paragraph 17, below).
3. Additional autism-specific training for individual team members has been costed from discussions with team members and specialist training providers, assuming full DISSC diagnostic training (approximately £3,250) for psychologists, training in TEACCH (approximately £1,000) and PECS (approximately £400) for speech and language therapists and a two-module specialist university qualification for other team members (approximately £1,100). These one-off autism-specific training costs have been summarised over the individual’s working life using the same method as Curtis.
4. The full breakdown of salary, on-costs and overheads for secretarial/administrative support is not listed in Curtis, but an overall cost of £28,011 is attributed as an overhead when costing senior clinical staff (e.g. p.160). We have therefore assumed this unit cost for such support in calculating the total cost of teams.
5. We have applied general overheads to support workers at a comparable rate to other team members, but because they will be largely community-based, have not included capital overheads for these staff.

The National Audit Office (NAO) investigated public spending into adults with autism 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 High Functioning Autism and Asperger syndrome 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 autism teams, thus achieving a cost-neutral level of service is an entirely realistic prospect in the medium term.

Although an initial cost with identification will be placed on the NHS – estimated to be around £28m for an eight per cent identification rate – the saving for local authorities would potentially be around £105m.

With health and social care being more closely integrated – because of the NHS reforms – this amounts to real savings for the NHS in the medium to long term.

As such, in the new social care funding system, the NAS believes money should be made available – paid for through joint health and social care budgets – for specialist autism teams.

**Autism Act 2009**

“Adults with autism remain socially and economically excluded. They, and the people who care for them, have often been badly let down by public services which have failed to recognise or respond to their needs.” Fulfilling and rewarding lives: The strategy for adults with autism in England (2010).

Following the *I Exist* campaign, in late 2008 Cheryl Gillan MP agreed to take forward a private member's Bill on autism in Parliament. Once passed, the Autism Act 2009 put two key duties on the Government. The first was to produce a strategy on services for adults with autism. This was published in March 2010 (www.autism.org.uk/dhstrategy). The second was that statutory guidance for local authorities and local health bodies had to be published by the Secretary of State for Health by the end of 2010. The Act stated that the aim of this guidance was to secure implementation of the strategy.

On 17th December 2010, the statutory guidance was published. This guidance sends a clear message that local authorities and the NHS must improve:

- training for their staff
- identification and diagnosis of autism in adults
- planning of services for people with autism, including the transition from child services to adult services
- local leadership

As this guidance is statutory, it is to be treated as if it were issued under section 7 of the Local Authority Social Services Act 1970. Therefore, local authorities and NHS bodies must follow the guidance when it is relevant to them and, unless a good reason can be given, can be challenged through the courts.

Given the tight economic climate, unlike Valuing People Now, very little new money has been made available to implement the strategy and statutory guidance. Indeed, only £500,000 has been made available for training materials and awareness raising.

Although the NAS believes that if money were to be made available local authorities and the NHS would be implement the changes necessary more quickly, we are keen to stress, if implemented fully, the strategy and statutory guidance can help save money in the long run.

In terms of the Commission’s work, therefore, we think there is a clear case to be made to spend-to-save. There is recognition of a real need, a cross-departmental strategy and statutory guidance telling local authorities and the NHS what they should be doing to make sure action is taken. There is, however, no money associated with any of this and we would suggest that the Commission recognise this and made recommendations to Government that funding is provided to local authorities and the NHS to implement the adult autism strategy and statutory guidance in full.
Economic cost of autism
To support the spend-to-save argument outlined above it is also important that the Commission fully considers the costs of autism. It has been estimated that:

- For someone with high functioning autism or Asperger syndrome the undiscounted lifetime cost was £3.1m, and the discounted cost £796,050\(^{14}\)
- For someone with autism and a learning disability the cost was 50% higher at £4.6m (undiscounted) and £1.23m (discounted).\(^{16}\)

These conservative costs do no include informal care by families. We believe that this cost must also be taken into consideration by the Commission.

To mark Carers Week 2009 the National Autistic Society (NAS) carried out a survey of the carers of people with autism. Over 300 carers responded to our survey and the results show that whilst caring for someone with autism can be incredibly rewarding, carers find themselves battling against a system that frequently fails to recognise their needs and leaves them feeling frustrated and ignored.

Across the UK 21% of carers spend over 50 hours a week caring.\(^{17}\) However, of those caring for someone with autism who responded to our survey, a staggering 83% care for over 50 hours a week. The majority of these carers were spending over 70 hours a week caring, with 68% of respondents providing over 70 hours of care a week for someone with autism.

Despite the high level of care and support provided by carers, Carer’s Allowance, the main benefit for carers, is paid at just £53.90 per week. To qualify for this allowance, carers need to be caring for a minimum of 35 hours a week which works out at just £1.54 an hour. However, when it is considered that the majority of our respondents were spending over 70 hours a week caring for someone with autism, this equates to just 77 pence an hour. In contrast, Jobseeker’s Allowance is paid at £64.45 per week: over the course of a year this works out as a difference of just under £550.

It is also essential that the Commission fully takes into account that just 15 per cent of adults with autism are in full time employment. This means that few adults with autism will be able to contribute towards cost of their care. Therefore however the Commission models new ways by which to charge individuals for their own care and support, this approach will have minimal impact on disabled adults of working age as by and large they simply do not have enough money to contribute.

As a result, the vast majority of the social care spending for this group will always come via core funding. When this core funding is insufficient, as is currently the case, the solution has to be to increase investment from central and local government. Increasing individual charges for this

\(^{14}\) The discounted rate is 3.5% - the amount recommended by the Treasury for public sector investment projects


\(^{16}\) Ibid.

group will generate minimal additional income, and will put large financial burdens on many individuals and families who already struggle financially.

Debates on social care have become overly focused on how individuals can pay for their own care in their old age. The lifelong needs of people with a disability have taken a backseat and this needs to be addressed urgently.

The NAS firmly believe that the Commission must consider the cost a disability has both on the individual and the family/carer. If people are economically disadvantaged, because of their caring role or their disability, the future funding system must take this into account.

Cost savings
Alongside its assessment of the importance of specialist teams, the NAO report details the main ways in which spending on autism is being wasted or a lack of investment leads to more costly care in the long run.

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. 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.

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.

Preventative services
Given the right support many more people with autism and particularly those with high functioning autism or Asperger syndrome will be much more able to live more independently in the community. Without this support, there is a far greater risk of social exclusion and therefore health problems, particularly mental ill health, developing.

We know that adults with autism 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. A third of adults with autism responding to our I Exist survey said that they had developed serious mental health problems as a result of a lack of support. As the NAO 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.”

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.

The table below is taken from the *I Exist* research and highlights the difference between what people want and what they are actually able to access. It shows, for instance, that there is a gap of 29% between those who have access to social skills training and those who want it, a gap of 28% between those who have a befriender and those who would like one, and a gap of 26% between those people who are able to access a social group compared with those who actually do.

One example of such a social skills scheme is the Socialeyes programme, a project run by the NAS to teach social skills to people with on the autism spectrum, in particular for people with Asperger syndrome. This learning resource has been developed with people with autism and Asperger syndrome, alongside leading professionals in the field. All Socialeyes resources have been extensively piloted and re-piloted with ongoing development and research since 2005.

Socialeyes does not ask people on the autism spectrum to change ‘inappropriate’ social behaviour, or to acquire social skills by copying the ‘typical’ behaviour of others. Instead, it gives people the option of learning social interaction skills or alternative social strategies. Socialeyes focuses on eight social skills that people on the autism spectrum can have difficulty with, including starting a conversation, eye contact and personal space.

In a service of last resort, services such as this are often seen as low-level in nature. While this may be true in relation to the relative cost and time spent in providing it, it is not low-level in terms of the impact it has on the lives of adults with autism – it is a lifeline.

<table>
<thead>
<tr>
<th>Support people receive</th>
<th>Support people would like to receive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social groups</td>
<td>Social skills training</td>
</tr>
<tr>
<td>Daily living support</td>
<td>Employment support</td>
</tr>
<tr>
<td>Advocacy</td>
<td>Day services</td>
</tr>
<tr>
<td>Befriending</td>
<td>Counselling</td>
</tr>
<tr>
<td>Education</td>
<td>Adaptations to home</td>
</tr>
<tr>
<td>Speech and language therapy</td>
<td>Mental health/pyschiatry</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>Other</td>
</tr>
<tr>
<td>Social skills training</td>
<td>None</td>
</tr>
</tbody>
</table>
Therefore, the NAS firmly believe that not only is there a strong case for funding preventative autism specific projects to avoid needs from escalating. The country currently spends nearly £28bn on children and adults with autism and a significant proportion of this is wasted on services that do not meet their needs. In particular, the NAS believe that local authorities need to fund social support services, including befriending, social programmes, social skills and skills training for adults with children.

**Employment support and social care**

NAS research has found that whilst many people with autism want to work just 15% of adults with autism are in full time paid employment.\(^{19}\)

Research has proven that effective employment support can work for adults with autism. Prospects, the NAS’ employment support service, found that the service was able to successfully place 67% of its clients in appropriate work environments in 2004.\(^{20}\) The follow-up study on the service revealed that over 85% of the jobs gained were sustained (over 13 weeks) and clients reported good satisfaction levels, increased confidence and improvements in independence.\(^{21}\)

The latest statistics from Prospects reveals that over any given 12 month period, the service supports between 30% and 35% of job seeking clients into work. Over a three-year period, this figure rises to around 70%. This means that between 30% and 40% of job seeking clients require 1 to 3 years to get into work. Therefore programmes for jobseekers with autism need to be (a) significantly longer than programs for other disabled jobseekers, and (b) funded accordingly.

For some people with autism, the skills that they need to develop to get into work are likely to be identified as a need in a community care assessment. In particular, there is some overlap in the support provided by work preparation programmes, particularly social skills training, and the support needed by some adults with autism from social care to live more independently in the community.

We recommend, therefore, the DWP allocate money to local authorities to fund autism-specific support, including employment preparation, social skills and self-advocacy training, which will provide both social care and support employability. This would be similar to the £1 billion transfer of NHS funding to social care in consideration of the health benefits which will accrue, announced by DH in October 2010.

**Case study: Prospects success stories**

Tomas has Asperger syndrome and dyslexia and, before contacting Prospects, had been unemployed for two years.

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Tomas was determined to find paid employment and joined Prospects’ work preparation programme. As part of the programme, he attended group and one-to-one sessions which covered the areas he found difficult, including time management; understanding instructions; and communicating effectively at work.

At the same time, Tomas started a six-week work experience placement at WHSmith. Here, he developed skills in a busy retail environment such as teamworking, customer service, stock control and time management. WHSmith were positive about the work Tomas did, which boosted his confidence.

Tomas continued to come to Prospects to attend job-finding sessions. He became more confident about completing application forms (previously, having dyslexia meant that he found this an obstacle) and going for interviews and, in due course, secured a temporary full-time job with Habitat, working as a stock assistant.

At Habitat, Tomas learned how to store and arrange stock, and became friends with his close colleagues. We gave his managers information about supporting staff with Asperger syndrome, and visited Tomas twice during his initial placement.

Habitat took Tomas on as one of 25 Christmas employees, but offered him a permanent post the following year. Tomas is very happy in his job and no longer needs support from Prospects staff.

**Personalisation and autism**

The NAS is supportive of the personalisation agenda. Giving more choice and control to the individual over how their care is organised and how the budget is spent is an aspiration which we share and endorse. We therefore welcome the Commission’s recognition that any reforms to the future of social care funding should support personalisation.

We would caution, however, that 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.

Largely this is around the implementation of the personalisation agenda and around the roll out of personal budgets in particular. We would like to highlight the following concerns to the Commission to consider as they develop any recommendations in this area:

1. Lack of information on how personal budgets work for people with autism
2. Resource Allocation Systems (RAS)
3. Support Brokerage
4. Marketplace development
5. Real choice based on accessible information.
6. Safeguarding
7. Person-centred plans based upon aims and aspirations
i) Lack of information on how individual budgets (IBs) work for people with autism
There is very little data and information on how well personal budgets 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.

With this in mind, it is important that the Right to Control pilot projects – the so-called Trailblazers – being run in seven local authorities 22 coordinated by the Office for Disability Issues looks at the outcomes of people with autism as a distinct category. If this opportunity is not taken, then the NAS fears that people with autism and those with complex needs will be left behind by ever evolving personalisation agenda.

ii) Resource Allocation Systems (RAS)
The way that a 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 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 personal budgets highlights that while their introduction can result in significant cost savings, the overall losers are people with “higher and more complex needs”. 23

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. 24 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.

Additionally, 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.

Consideration is needed about the support that will be given to service users to accurately fill out self assessment forms. Where people with autism are being supported to fill in a

22 Essex County Council, Leicester City Council, Barnet, Newham, Epsom and Ewell Borough Council, Reigate and Banstead Borough Council, Barnsley Metropolitan Borough Council and Sheffield City Council.
questionnaire, the individual providing the support must be trained in autism to understand that 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. 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.

To emphasis this point, one example of a RAS is Stockport’s, which can be found here: http://www.mycaremychoice.org.uk/self-assessment.aspx. This RAS is designed in conjunction with a company called ‘Quickheart’ who specialise in developing customer journeys for websites. This is a self-assessment questionnaire that individuals or family carers can fill out which will then give you care and support options and will be followed up by the local authority.

Autism in all of its guises is an extremely complicated disability and these questions, which would be better suited to identifying need in for the physically disabled/elderly, are not appropriate for identifying need in individuals with autism. The NAS recognises the need for such self-assessment forms. We do, however, worry that increasingly RAS forms like Stockport’s are becoming the determinant for support due to an over reliance on self-assessment.

Councils must not use these forms as a barrier to service and the NAS has been increasingly concerned to hear stories from our helpline and other charities about social workers using such forms in face-to-face meetings and as a reason for not offering support. This is contra to legal advice we have received, which states that in social care law such a self-assessment process is illegal.

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

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, again, 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.

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25 We do not use Stockport as an example of bad practice necessarily, not least because the NAS works closely with Stockport Council through the Greater Manchester Autism Consortium and they do a lot of good work with people with autism.

26 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.

In conjunction with other disability charities\(^{28}\) the NAS has produced a document called *Putting Everyone First*. *Putting Everyone First*\(^{29}\) 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.

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.

**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.

**iii) Support brokerage**

For some people support brokers will be an essential support in a new system, where 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. Appropriate support brokerage must therefore be made available locally, perhaps through the specialist autism teams we wish to see included within the adult autism strategy, or by local authorities working in conjunction with the voluntary sector.

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.

**Case study: A brokerage service for adults with autism on personal budget**

Bury Metropolitan Borough Council recognised that there was this gap in support for people with autism, and Bury Adult Care Learning Disability Partnership Board funded a support brokerage role. They invited tenders from different organisations to manage and run a two-year £80,000 project and the NAS was successful in winning the contract. To our knowledge, this is the first autism-specific support brokerage to be set up in the UK.

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\(^{28}\) The other charities are Sense, Royal National Institute for Deaf People, Royal National Institute of Blind People, Mencap and Guide Dogs.

One full time member of staff was employed as the support broker who started in June 2009 and will run until June 2011. This broker aims to support people to:

- Identify the changes they want to make to their lives
- Undertake individual support planning
- Find the support services and community opportunities that the person requires
- Negotiate with providers
- Identify and obtain funding, including securing agreements on Social Services funding.
- Provide information and support leading to the recruitment and selection of Personal Assistants.
- Initiate the implementation of individual plans.

The brokerage service aims to benefit people with autism living in the area of Bury in a number of different ways:

- By providing people with more choice and control over the services they receive and in their own life in general
- By developing local services for local people and stimulate the market. It is hoped that people will then be able to choose which area they wish to live in rather than having to access services out of county.
- By providing people with information, which ultimately provides people with more power and the ability to make informed decisions. Money can then be used in a way that makes most sense to the person

Currently, in order to evaluate the project, the Action Research Leader at the NAS is undertaking in-depth interviews with service users, family carers, social workers and those involved in the project. This research will shortly be published, but the quote below is illustrative of the positive feedback we have received.

“Q: What would you tell other people who are thinking about using a brokerage service?
A: Use it! Actually I think I’d be quite stumped without it.”– Mum of supported adult with autism”

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.30

We believe that Autism Partnerships Boards should be developed and these would help 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 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 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.

vi) Safeguarding and the personalisation agenda
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 IBs pilot had anecdotal evidence of users of direct payments and possibly IBs being subject to financial abuse from family members or paid carers. A team manager interviewed as part of the

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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 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 individual’s contract with the accountant, thus safeguarding against 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 need 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.

Local authorities also need to take greater responsibility and should regularly review support plans and the arrangements that have followed those plans to help pick up on financial and other abuse, much earlier.

vii) 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. 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. 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.

We urge the Commission to ensure that it fully considers the pitfalls of the implementation of personalisation as it makes recommendations in this area.

Conclusion
In theory, the NAS would like to see universally free access to social care, but we recognise that this is unlikely to be an option.

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Given the lack of publically available information on the future costings for care and support, particularly for those with disabilities, we were unable to properly evaluate the merits of the different options. However, we do believe that there are a number of principles that should underpin the allocation of funds. The maximum numbers of people should be able to access the maximum amount of support depending on need and that the funding for care and support must be fair and transparent. Some people may have to contribute towards their care packages, but it should be remembered that it is very unlikely that someone with a lifelong disability will have the means to contribute towards payment for their care. It should not be assumed that their families will able (or willing) to pay.

The Commission needs to look at how it can increase funding for care and support, through re-prioritising funding plans. Investment in preventative services should move higher up the agenda, as these services can help save money in the long-term.

Furthermore, much more needs to be done to support people with autism to find work and this needs to been seen in isolation of social care.

Finally, additional pressures cannot, and should not be placed on unpaid carers. Indeed, they need further support, including improved access to short breaks and a Carer’s Allowance that fully reflects their contribution to society.
Appendix A

Specialist Autism Teams

“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

What would the specialist autism team do?

“The Liverpool Asperger Team are a team of professionals who provide a specialist service for people with Asperger syndrome, adopting a person-centred approach and using creative and innovative interventions to assist the individual with the social and communication barriers that they may face in everyday life.”

Liverpool Asperger Team Mission Statement

The NAS recommends that the teams have 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.

They should be tasked with improving provision for adults across the whole autism 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 these teams and waive their own responsibilities. Indeed, the opposite is true in that perhaps the most significant function of the team lies in building capacity for supporting adults with autism within mainstream services.

More detail on the role of specialist autism team

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 signposting 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.\(^{33}\)

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.\(^{34}\) 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.

In the NAS opinion, specialist teams 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 team 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 team must also establish a clear and transparent referral pathway for diagnosis and support to compliment this work. Having this team and process in place, would also help local authorities and the NHS meet their duties under Autism Act 2009 statutory guidance.

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%)\(^{35}\). 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.\(^{36}\)

Clearly these teams 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 would be in building capacity among existing services and professionals to better support adults with autism.


\(^{34}\) Ibid.


\(^{36}\) Clark et al. (2009) *Supporting people with autism through adulthood*. The National Audit Office.
The team 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. Again, having a team in place would help local authorities and the NHS meet their duties under Autism Act 2009 statutory guidance.

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 teams 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 would provide direct support with assessments where needed. For individuals for whom social services do not have sufficient expertise to carry out an appropriate assessment, someone from the team 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.

The team 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.

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

As shown above, 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.

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

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 teams 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 team 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.

6. Build local capacity around employing adults with autism
Improving employment outcomes for adults with autism must be integral to the remit of the team. 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.

Summary of the role of the specialist autism teams
In summary, these teams 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.

Where would the specialist autism teams be located?
Ideally, the specialist team would 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 NHS and the local authority is mandatory. A genuinely joined-up approach to funding and delivery is necessary for this team to successfully deliver. As such, as part of the wider NHS reforms currently ongoing, these teams are most likely to be commissioned by Health & Wellbeing Boards in the future.

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.
Appendix B

Autism Spectrum Condition Adult Care Pathway

Person or family/carer

General Practitioner, Secondary/tertiary healthcare, Prison mental healthcare, A&E and liaison, NHS Direct, Social services.

Person in transition with diagnosis

Is person eligible for Mental Health or Learning Disability Services?

Yes

MH/LD team undertake:
- Diagnostic assessment
- MDT assessment of need
- Community care needs assessment

No

Presence of non-severe/longstanding MH problems?

Yes

Need for specialist tertiary services?

No

Treatment by secondary services

Yes

Treatment by tertiary services

Service user support
- Post diagnostic support
- Liaison
- Preventative interventions
- Signposting

Diagnostic assessment
- ASC diagnosis given?

No

Yes

Workforce support
- Consultation
- Supervision
- Training

Discharge &/or signpost & refer if needed

Financial Management
Education & learning
Accommodation
Employment
Support networks
Social networks