

Ignored or ineligible?



*The reality for adults with  
autism spectrum disorders*



THE NATIONAL  
AUTISTIC SOCIETY

action for autism

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Aidan Prior

Ignored or ineligible?

## **Acknowledgements**

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Judith Barnard

Front cover photographs (by Steve Hickey and Jake Williams) feature some young adults on the autism spectrum who receive the kind of support others need: contact social groups, supported service accommodation and employment support (NAS Prospects).

The DfEE is supporting the development of Prospects in London, Glasgow, Sheffield and Manchester over the next two years.

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## *The reality for adults with autism spectrum disorders*

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The National Autistic Society report for  
Autism Awareness Week 2001

Judith Barnard Virginia Harvey David Potter Aidan Prior

We have used the terms ‘autism’, ‘autism and Asperger syndrome’, ‘autism spectrum conditions’ and ‘autism spectrum disorders’ throughout this report to refer to all autistic spectrum disorders. However, in places we will refer specifically to ‘people with Asperger syndrome’, referring to the adults with this diagnosis (48% of the sample). Unless mentioned otherwise, all findings relate to the entire autism spectrum.

Throughout this report people with autism spectrum disorders have sometimes been described as ‘lower’, ‘medium’ or ‘higher functioning’. This relates to a question asked of all respondents as to the ability of their son

or daughter with autism or Asperger syndrome. We appreciate that while some people with autism and Asperger syndrome may refer to themselves in these ‘medical’ terms, they may cause offence to others.

However, these terms were used for data collection as a more useful indicator of ability than the actual diagnosis received. ‘High functioning’ or ‘very high functioning’ relates to the more able end of the autistic spectrum where the true level of disability and vulnerability may be masked by an average or above average intelligence. ‘Lower functioning’ relates to the less able end of the spectrum, where people may also have an additional learning disability.

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People with autism or Asperger syndrome are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with autism or Asperger syndrome must no longer be marginalised or excluded. The National Autistic Society carried out research amongst the parents of 1200 adults with autism or Asperger syndrome. Over 450 (38%) responded and the findings are published in *Ignored or ineligible? The reality for adults with autism spectrum disorders*.

This report describes the situation for adults with this complex disability, and their families, across the UK. It highlights the fact that the majority of people on the autism spectrum have been excluded from the recent Learning Disability Strategy in England and Wales (although this is not the case in Scotland) as they are of average or above average intelligence. The report therefore makes recommendations for the Government to address this as a matter of urgency at a national, regional and local level, so that **all** people with autism spectrum disorders throughout the UK are able to access the vital services they need.

## Rights

People with disabilities have a right to have their needs assessed by their local authorities, yet only 38% of people with autism and Asperger syndrome have a **community care assessment**. Only 16% were actually offered one; others had to ask or fight for one. Although the process of assessment was good, with a high degree of consultation with families, only 45% are actually receiving the services specified in the assessment.

Similarly, at the point of transition from adolescence to adulthood, a little over half of families (53%) had a **transition plan** in place. Again, a helpful and consultative process for families, and yet only 16% have had their identified needs met in full.

There was a significant pattern of **late diagnosis**, across the whole autism spectrum. Only 43% of

lower functioning adults were diagnosed before the age of five, despite their urgent needs. 18% of lower functioning adults were not diagnosed until beyond the age of 16. At the higher end of the autism spectrum 46% of people with Asperger syndrome were not diagnosed until over the age of 16.

There was a strong correlation between early diagnosis and satisfaction at school. Of those parents whose children were diagnosed before the age of five, 67% said they were satisfied with their primary education, whereas for those whose children were not diagnosed until adulthood (20+) only 21% expressed satisfaction with primary education. Similar patterns followed at secondary level.

Parents expressed their confusion as to which statutory agency was responsible for their son or daughter's welfare: 59% agreed that **responsibility** for funding and providing care and support **fell between agencies**. Two-thirds (66%) of those who had had a community care assessment said that they had no lead agency responsible for their adult son or daughter. Finance was thought to be the primary reason for this.

Autism spectrum disorders constantly fall through **the gap between mental health and learning disability** services for most people at the medium or higher functioning part of the autism spectrum.

Health and social services are **not meeting their statutory responsibilities** to participate in transition planning: the health authority was only involved in 11% of plans and social services in 33%. Joint working between health, social services and education is not happening.

## Independence

70% of parents felt that their son or daughter would be **unable to live independently** without support. Less than 10% of adults can manage the most basic household tasks such as shopping, preparing meals, laundry, paying bills, managing money, without help.

49% of adults with autism or Asperger syndrome are **still living at home** with their parents. 65% of these adults have had no community care assessments and are therefore unlikely to be known to the statutory agencies who should be supporting them.

31% of adults at the lower end of the autism spectrum are still being cared for at home, despite their high level needs. 45% of parents believed their son or daughter required **24-hour care**, and only 15% thought they could live in sheltered or shared accommodation.

Only 3% of adults at the higher end of the autism spectrum are living fully independently, and a further 8% are living independently with some regular professional or family support.

Families are shouldering **the burden of care** for their adult sons and daughters, most of whom are unknown to health and social services.

## Choice

People with autism or Asperger syndrome have very little choice in where they live, what work they can do and who looks after them. Only 2% of adults at the lower end of the autism spectrum and only 12% of higher functioning adults are in **full-time paid employment**. A quarter (24%) are **doing nothing** at all or 'helping out around the house'.

Over a third (35%) of parents said that the whole issue of housing for their son or daughter was not adequately addressed through the transition planning process. This may explain why so many adults are still living at home with their parents.

Only 19% of adults had access to any sort of **advocacy** when their future was being decided upon to help them express their own views about their choice of care, housing and activities. 70% of parents said they did not believe that their son or daughter had understood the process or the implications for their adult life.

## Inclusion

Two-thirds (65%) of parents said that their sons

and daughters had **difficulty making friends**. And only 7% said that their son or daughter had no need of friends. Almost a third (31%) are involved in **no social activities** at all.

Only 28% of adults have had any access to **social groups** for people with autism and Asperger syndrome. 71% of parents thought their sons or daughters would benefit from such a group.

72% of parents said that their son or daughter had behaviours which other people find unusual or anti-social. 82% believed that their son or daughter would benefit from **social skills training**, but only 44% had received any.

## Consequences

A third (32%) of parents reported that their son or daughter had experienced **mental ill health**. This rose to half (50%) of those whose son or daughter was not diagnosed until after the age of 30.

Of those experiencing mental ill health 56% had **suffered with depression**, a further 11% a **nervous breakdown** or near nervous breakdown, and 8% felt **suicidal** or had attempted suicide.

The effects on families were also devastating: **families were excluded** from any 'normal' life. They reported that families' social lives were destroyed, including holidays; frequently one parent had to give up their career to care for the child (then adult) at home, siblings were neglected, marriages torn apart. The emotional stress is devastating. Most parents fear what will happen when they become too old or frail to care for their son or daughter.

## Conclusion: Ignored or Ineligible?

Statutory agencies are failing adults with autism and Asperger syndrome. The majority of individuals and their families are excluded from the care system. They are either ignored or discriminated against through rigid eligibility criteria, often established through ignorance of

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autism spectrum disorders. In particular, the critical period of transition from adolescence into adulthood is breaking down, and parents are picking up the pieces.

## Recommendations

The Government should issue national guidance to all relevant agencies that clarifies their statutory duties and responsibilities to address the specific needs of people with autism spectrum disorders. This guidance must tackle these needs holistically, at a national, regional and local level, and ensure effective and accountable joint working across all agencies, to achieve agreed objectives.

The guidance should cover:

- Health services
- Diagnostic services
- Social services
- Education
- Housing
- Transport
- Benefits
- Employment
- Advocacy
- Forensic services
- Training of all relevant practitioners.

This guidance should be accompanied by a dedicated funding stream, conditional upon multi-agency collaboration. This guidance should be widely promoted and made accessible, for example through a national conference and a dedicated website.

The National Autistic Society will lobby central and local government policy-makers to take action to meet these needs.



**A**utism Awareness Week has long been an opportunity to highlight the concerns and experiences of those affected by autism or Asperger syndrome.

In past years The National Autistic Society's research has covered issues such as education, diagnosis and inclusion. Given that these areas mainly covered children a greater concentration on issues affecting adults was overdue.

This research aimed to investigate the reality of 'joined up' provision for the adult population. Are services experienced in a seamless way? Do the traditional boundaries for funding continue to apply?

The findings paint a very grim picture of the reality facing adults with autism and Asperger syndrome and the serious impact on their families. They highlight these adults' needs, across the whole of the autism spectrum, whether they are of below average, average or above average ability. It demonstrates that they are currently excluded from many of the services which should be available to them, and excluded from employment and social activity, through ignorance or deliberate discrimination. It also shows that the majority of parents (carers) of these adults are excluded from services and from society as a result.

## Background & methodology

The power of members' stories has been observed from previous research and the questionnaire was designed in such a way that these stories could be extracted. As in previous years a small panel of members in the target category (n=8) was brought together to comment on an initial draft and to indicate their main areas of concern and experience. This enabled the final questionnaire to be more appropriately worded and designed. We also sought the advice of several practitioners in the autism arena. Following from this we were informed by three pieces of similar research done at local authority level (Moohan 2000; Powell 2000; Brogan 2001).

This year the work has focused on two questionnaire surveys. The first was sent to a sample of

members of The National Autistic Society who have adult children with autism spectrum conditions. A total of 458 responses were received out of 1200 mailed, a response rate of 38%. Of these responses 450 were analysed by NOP Numbers to 95% and 99% confidence levels. This highlighted the most statistically significant findings and it is these that have been used as the basis for this report and its recommendations.

The questionnaire covered thirteen A4 pages and could be completed anonymously. Many respondents took up to half an hour to complete it. A prepaid envelope was provided to encourage responses. Many of the answers provided gave unprompted responses which, when seen together with those of their peers, have much greater impact and indicate real concerns. The sections covered details about the adult child and their experience through the education and health systems, and their everyday life, their interactions and social behaviour, transition planning, community care assessment and services provided by The National Autistic Society.

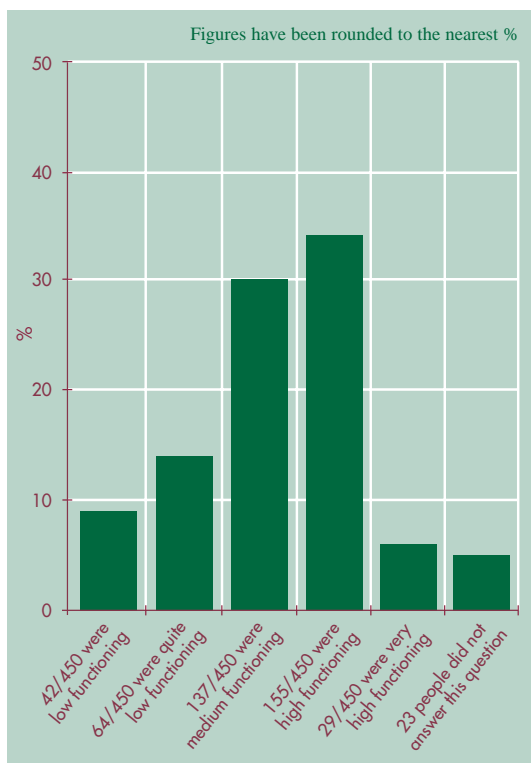
The second survey was on a far smaller scale and was designed specifically for adults with autism spectrum conditions themselves. This was distributed via various National Autistic Society projects working with people affected by the condition. These were in Wales, Scotland and England (mainly London, Bristol and Northamptonshire). The projects were adult centres, supported employment projects and social groups. There were 38 responses completed by the adults themselves or with help from their support worker or primary caregiver, generally a parent.

This survey also covered personal information about the respondent and their experiences of education and diagnosis, their present life situation and their level of satisfaction with it, benefits, hobbies and social life and services. These adults are at the higher functioning end of the autism spectrum and whilst their views are not representative of adults across the whole spectrum their views give a poignant insight into individual experiences.

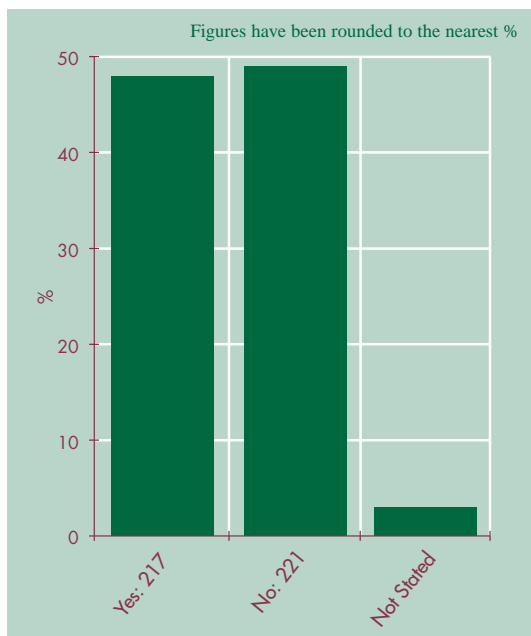
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## Profile of respondents

As the autism spectrum covers a large range of abilities it is common for professionals to describe individuals as low, medium or high functioning. Whilst acknowledging that this description offends some, we asked parents how they would describe their son or daughter. This is the profile:



We also asked how many had a diagnosis of Asperger syndrome:



## Ineligible for inclusion

In March 2001 the Government published its Learning Disability White Paper *Valuing People*. This was heralded as a new strategy for the 21st Century, the first to address issues for people with learning disabilities in 30 years. In Scotland, the Scottish Parliament's Learning Disability Review *The Same as You?* was published in May 2000. In Scotland, autism spectrum disorders are included in this strategy – and indeed have been given particular reference. However in England and Wales the definition used by the Government has specifically excluded people with autism spectrum disorders where there is no accompanying learning disability. This has immediately disenfranchised over half the people on the spectrum, many of whom are currently receiving some limited services from learning disability teams.

In practice the definition of a learning disability used in the White Paper applies across the whole autism spectrum – although perhaps the term 'developmental disability' would be more appropriate.

*The White Paper defines learning disability as:*

- 'A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development.'

The survey findings have been divided into four main sections using the four key principles of **Rights, Independence, Choice** and **Inclusion** which lie at the heart of the Government's proposals in *Valuing People*.

The picture painted by this survey shows that there is a long way to go before these principles are a reality for adults with an autism spectrum disorder – even those at the lower end of the spectrum who may also have an accompanying learning disability. For those at the higher end, excluded from the Government's definition of learning disability, this report will demonstrate that they have similar needs, and yet are

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discriminated against by the statutory authorities. The White Paper serves only as a further excuse for authorities to exclude people with medium to higher functioning autism from their services – but without offering any alternative provision to this needy and vulnerable group.

Both this deliberate exclusion of people with higher functioning autism and Asperger syndrome, and the narrow definitions used by public services to define mental health and learning disability services, fail to serve the needs of people with an autistic spectrum disorder in practice, and are of grave concern and must be addressed.

This report will show why – and will make recommendations as to how this discrimination can be redressed.

The Learning Disability White Paper *Valuing People* highlights legal and civil rights as the first of the four key principles at the heart of its strategy:

*'The Government is committed to enforce-able civil rights for disabled people in order to eradicate discrimination in society. People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary...All public services will treat people with learning disabilities as individuals with respect for their dignity, and challenge discrimination on all grounds including disability. People with learning disabilities will also receive the full protection of the law when necessary.'*

So what is the picture for adults with autism spectrum disorders?

### The right to services

The main route by which adults with a disability can expect to access social services is through a **community care assessment** (NHS and Community Care Act 1990). However, only 38% of people with autism and Asperger syndrome have had a community care assessment. Almost half (48%) of lower functioning adults have not had a community care assessment at all, despite their clearly identifiable needs.

*"They were helpful in as much as they were honest, i.e. after 19 you are on your own as there are no legal requirements for services – we're not going to provide any."* (Parent)

Local authorities are expected to identify people with disabilities who need services. People with a disability have specific rights to services through the community care assessment process – and yet only 16% of the parents responding to the survey were offered an assessment. Others had to request or fight for one.

*"The greatest difficulty is an emotional one. Appropriate provision is not made available*

*without a fight, and as a parent you are fighting for something that in your heart you don't want. You must recognise how disabled and vulnerable your child is, and force others to do so."* (Parent)

Parents whose son or daughter had a community care assessment found the process a good one, as there was a high degree of consultation with families. But only 45% are actually receiving the services specified as a result. And a further 38% had not had any review or reassessment.

*"We have had to make most of the running. Although Peter is on the disability register we have had no contact with or from social services at any time."* (Parents)

### Moving into adulthood

*"What will happen when he leaves college at 19?"* (Parent)

The survey found a similar pattern in **transition planning** at school. Only 53% of those in the relevant age group actually had a transition plan in place. Where transition planning had taken place, parents found this to be a good process with a high degree of consultation with families. Yet only 16% had their identified needs met in full, with a further 38% having them met 'mostly'. But 12% said they had not had their identified needs met at all. Only 38% have had their plan reviewed.

*"I felt the overall "transition" plan was not very helpful. Once he left high school all support ended."* (Parent)

Information and independent support is now supposedly available to parents, particularly those with a child with special educational needs or a disability. Yet 69% of those with children aged 16-19 and with a transition plan in place have had no information about parent partnerships, and only 1% had parent partnerships involved in their transition plan.

*"We are about to embark on transition and I am scared stiff – there is a black hole facing us in 18 months time when school ends and at the moment I have no idea where to turn for help."* (Parent)

## Diagnosis: the key to accessing services

Late diagnosis is a significant pattern for people with autism across the spectrum. Only 43% of lower functioning adults were diagnosed before the age of five, despite having urgent needs which could be addressed through early intervention. 18% of lower functioning adults were not diagnosed until 16 or beyond.

Longer delays were experienced by some at the higher end of the autistic spectrum where 29% of people were not diagnosed until over the age of 16. This figure was much higher for people with Asperger syndrome where 46% were not diagnosed until post-16.

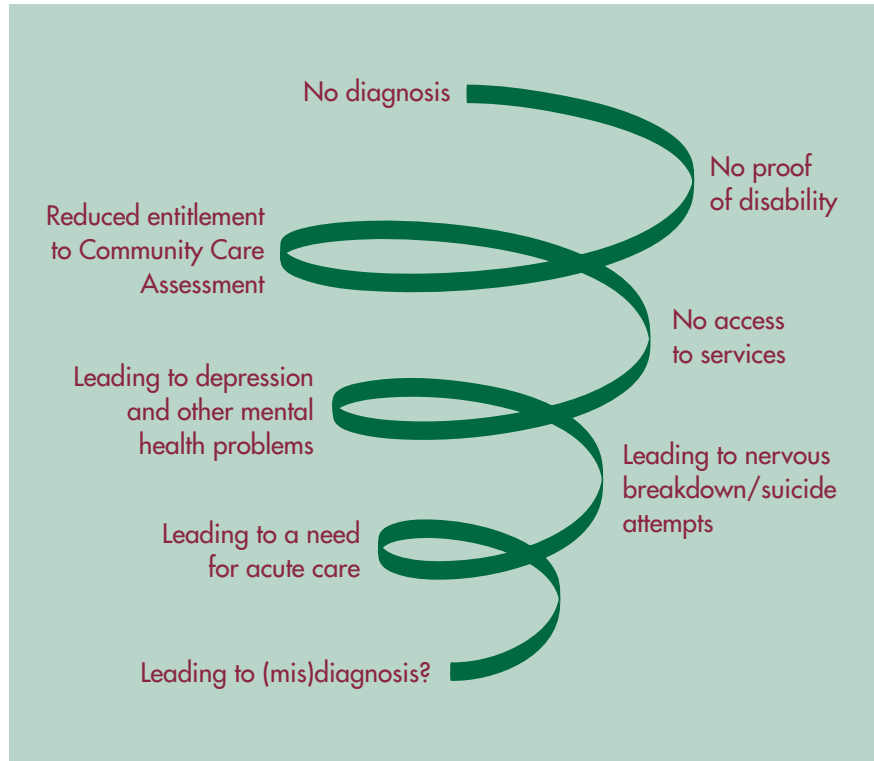
*“The local NHS paediatrician advised that ‘he can communicate...and so he is not autistic...what are you [parents] worried about?’”* (Parent of man in his 30s, medium functioning, diagnosed in his 30s, and who now has acquired mental health problems)

A strong correlation exists between satisfaction at school and diagnosis. Parents reported far higher levels of satisfaction where a diagnosis is already in place. For example, where children had been diagnosed before the age of five, 67% of parents said they were satisfied or very satisfied with primary education, compared with an average of 41% overall. The same pattern follows through at secondary level. Where diagnosis was made before the age of eleven, satisfaction levels were at 60% compared with an average of 42%. In contrast, where diagnosis took place after the age of 20 satisfaction levels were only at 21% at primary level and 13% at secondary school.

*“His difficulties were undiagnosed and unrecognised and he had a very hard time as a result.”* (Parent)

Feelings after diagnosis: *“Relief that I wasn’t mad.” “Relief, but angry at late diagnosis.” “Relief to have an answer, but upset and disturbed that I wasn’t ‘normal’ in the sense that I couldn’t cope as well as other people.”* (Adults)

## A common spiral



*“I only found professional help after I took an overdose.”* (Adult)

*“I suffered severe depressions resulting in self-injury, thoughts of suicide, hopelessness, failure and self-hatred. I couldn’t do anything for myself. I had to be told to wash and be taken to the bathroom and I didn’t eat and became very underweight. I was given various types of drugs and anti-depressants. I was diagnosed as a result of the depression. The first diagnosis was schizophrenia then severe clinical depression with suicidal tendencies.”* (Adult)

## Joint working?

There was a considerable amount of confusion as to which statutory agency was responsible for their son or daughter’s welfare. Overall 59% of parents agreed that responsibility for funding and providing care and support **fell between agencies**. This rose to 64% of the parents of people with Asperger syndrome, and to 67% of those at the very lowest end of the spectrum. Surprisingly, of those with a community care assessment in place, two thirds (66%) said they had no lead agency responsible for their son or daughter.

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*“We do not receive much practical help from our local social services. They just seem to pass on their responsibilities to whomever they can.”*  
*“Our daughter’s case was passed from LEA, to Social Services, to health like an unwanted parcel.”* (Parents)

*“I am the person who takes the lead. It is very time consuming and takes a lot of effort to get any help from Local Authority services. I appreciate that they have a limited budget, but people with Asperger syndrome are “juggled” from one department to another.”* (Parent)

When asked to give reasons for this confusion, 10% (unprompted) thought the primary reason for the lack of clarity as to which agency had lead responsibility was because of **financial concerns** – ‘who foots the bill’.

*“Seems down to finance – no-one admitted to having the funds in place to provide support. After lots of arguing and letter writing, support was provided.”* (Parent)

*“Although residential accommodation was available and both social services and health departments agreed that this was desperately needed, neither would agree to fund without a fight.”* (Parent)

Where a community care assessment was in place, social services were twice as likely to be the lead authority: 55% had services provided by social services, 28% by education and 26% by health.

*“Only through our constant badgering of ALL the various agencies (including the doctor) did we eventually arrive at the current, far from satisfactory, situation. We feel that in turn all the agencies let Joe down at some stage. We were the constant driving force.”* (Parent)

In practice people with Asperger syndrome receive either **mental health or learning disability services**. However, there is often no clarity of responsibility between the mental health and learning disability teams within social services, or between social services and

health. Parents are often passed from pillar to post when trying to access services and support.

*“Social Services have been bickering amongst themselves as to whether he falls under the mental health or learning disability umbrella. As you may have gathered they are going round in circles and not accepting any responsibility for Daniel’s care.”* (Parent)

Currently many people on the medium to higher part of the autism spectrum (and particularly those with Asperger syndrome) are assessed as being ineligible for Learning Disability services on the basis of having an IQ over 70, with no reference to their social and communication difficulties. They are then commonly passed to the mental health team, but are ineligible for support services until they suffer an acute deterioration of their mental health. The White Paper seeks to remove the IQ criterion, and replace it with a needs-led eligibility system, but specifically excluding those with higher level autism spectrum disorders. It states *“The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as people with Asperger’s Syndrome”*. Services are already being withdrawn by Learning Disability teams in some local authorities as a result of this. The Government should redress this urgently.

*“They didn’t think I was bad enough as my IQ was over 70.”* *“I had a social worker until I was 18. Social services have not been in touch with me since then.”* *“I went to a steering group meeting and they were unsure where Asperger syndrome belongs.”* (Adults)

*“Diagnosed at 20 by mental health and learning disability – both refused to offer any service. Not their responsibility.”* (Parent)

In relation to **transition planning**, social services and health did not feature highly in the planning process. A social worker was only involved in 33% of transition plans, and the health authority was only involved in 11% of plans.

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*“Joint funding and integrated provision would ensure a far more effective service. Social Services carries a disproportionate burden – and has always done so.” (Parent)*

This survey raises serious questions about the effectiveness of joint working. The evidence from this survey suggests that people with autism and Asperger syndrome are being passed backwards and forwards. There are **no clear lines of responsibility**. In particular the health service is far less involved in transition planning, community care assessments and service provision.

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The second key principle at the heart of the Learning Disability White Paper is independence:

*‘Promoting independence is a key aim for the Government’s modernisation agenda. Nowhere is it of greater importance than for people with learning disabilities. While people’s individual needs will differ, the starting presumption should be one of independence rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided.’*

## Keep it in the family

Independence for both the person with autism or Asperger syndrome and their family is limited – 49% of adults are **still living at home** with their parents. 65% of these adults have had no community care assessment and are therefore unlikely to be identified by social services or other statutory agencies as requiring any services or support.

*“Paul tends to get bored in the evenings and I have to try and find ways of involving him. He tends to get destructive and talks non-stop about one thing.”* (Parent)

Overall, a third (33%) of the adults are in residential care – and unsurprisingly this falls to 16% of people with Asperger syndrome. However, 31% of adults at the lower end of the autism spectrum are still being cared for at home by their parents.

*“We lived in hell too as each day followed the same pattern of huge violent, aggressive tantrums.”* (Parent)

## The autism spectrum: who needs services?

70% of parents felt that their son or daughter would not be able to live independently without support – this applied across the range of the autism spectrum. Significantly, this was not much lower for the most able (62% for

Asperger syndrome). In their parents’ opinion less than 10% of adults can manage basic tasks without help – preparing meals, housework, paying bills, managing money, shopping, laundry and dealing with letters.

*“She needs someone to call and see that she was not lying in bed all day, was making proper meals and not overwhelmed with bills coming in that she could not understand. Also to see she was taking her medication.”* (Parent)

*“My uneven abilities lead to unrealistic expectations in others.”* (Adult)

Activity	A lot of help needed	No help needed
Planning and preparing a meal	50%	8%
Housework	42%	8%
Paying bills	58%	3%
Managing money	56%	4%
Shopping	42%	11%
Laundry	45%	10%
Dealing with letters	31%	4%
Personal care	31%	8%

Many people on the lower part of the autism spectrum will require high levels of support. Parents of lower functioning adults did not believe that their son or daughter could live independently at all. 45% of families with an adult child at the lower end of the spectrum living at home believed they required 24-hour care (unprompted question), and only 15% thought they could live in sheltered or shared accommodation.

*“He cannot contemplate independent living. The thought terrifies him. Even to discuss it causes great distress. We are worried sick about his future. We have had to pick up the pieces so many times when there’s been a crisis. We are very tired. His inflexibility and rigid attitude to time keeping, meals, etc dominates our lives. Who is going to be there for him when we’re gone?”* (Parents)



*“He is 35. He still lives with us. We are now in our 60s – he needs to start living independently whilst we are able to support him. He stands no chance whatsoever of getting council accommodation in this area.”* (Parents)

Conversely, it is widely assumed that people at the higher end of the autism spectrum are able to function independently. As they appear to be able and articulate, statutory authorities often assume that they do not require high levels of support, and yet according to parents, they are often unable to live alone without help. But only 3% of people with Asperger syndrome are living fully independently (2% overall), and 59% are living at home with their parents (49% overall).

Over half need a lot of help paying bills and managing money and 40% need a lot of help in making a meal.

*“She now has a fiancé and they would like to live in the community, with help. Nobody seems to be really helping them.”* (Parent)

This demonstrates how families are often footing the bill for care – their adult children cannot live independently, and yet very few are accessing services or support. These **adults are ‘hidden’ from statutory agencies**, and yet in time they will need services when their parents become too old to continue to care for them.

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The recent Learning Disability White Paper *Valuing People* enshrines choice as its third key principle:

*‘Like other people, people with learning disabilities want a real say in where they live, what work they do and who looks after them. But for too many people with learning disabilities these are currently unattainable goals. We believe that everyone should be able to make choices. This includes people with severe and profound disabilities who, with the right help and support can make important choices and express preferences about their day to day lives.’*

What is the reality for people with autism spectrum disorders?

## Employment

Only 6% of adults are in full-time employment, with 4% in part-time employment.

24% are **doing nothing** or ‘helping out around the house’.

*“He sleeps most of the time.”* (Parent)

At the lower end of the autism spectrum only 2% of adults are in some sort of paid employment. However, despite their higher abilities at the other end of the spectrum only 12% of adults with Asperger syndrome are in full-time employment, with 6% in part-time employment.

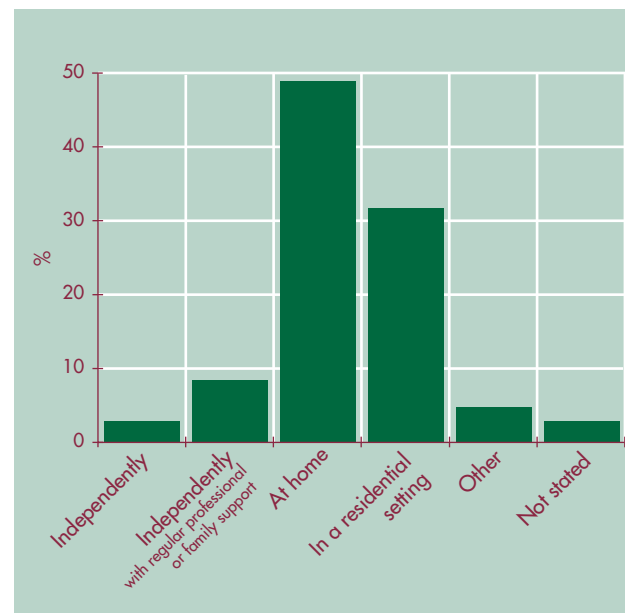
*“His biggest barrier: obtaining long term employment. All his jobs including the present one have been temporary and short term.”* (Parent)

The more able adults cited employment as the single biggest issue or barrier facing them. Half the sample were not in work and all but two wanted paid employment. Adults felt they had many positive merits to offer an employer – determined, hard-working, honest, punctual, reliable, qualified, bright, patient – were the main qualities cited.

*“I want a ‘proper’ job. Full-time employment.”*  
*“Preferably not doing unpaid voluntary work and instead working in a full-time permanent position in my chosen field.”* (Adults)

## Housing

Where does your son/daughter currently live?



Almost three-quarters (73%) of parents said that their adult child was happy where they lived. Only around half (54%) of the more able adults agreed with this. A third of the (more able) adults who took part in the adult survey were unhappy – the highest levels of dissatisfaction were expressed by those who wanted to live more independently. Yet only 8% of adults were living independently with regular professional or family support. Almost a quarter of people with Asperger syndrome would only need a few hours of support each week in order to be able to live independently. Cost-effective and flexible solutions can promote independence and encourage the person to seek employment – thus becoming a tax-payer, and reducing their need for welfare benefits support.

*“We need people who understand Dan’s behavioural problems and care for him as we do. All this in a small homely safe environment – but where he is encouraged to grow up and take control of his life.”* (Parent)

Choice for parents with adults at the lower end of the autism spectrum is also constrained. Given that only a third (33%) are currently in residential care and a further third (31%) are still living at home, 45% of whom require 24-hour care, options such as supported living are not a viable alternative. Consequently parents have little choice but to shoulder the burden of care themselves.

Within the **transition planning** process, housing was highlighted as a significant problem – 35% of parents said that this area was not adequately addressed. It has already been demonstrated in the section on Independence that in half the families surveyed their adult son or daughter is still living at home.

*“The local authority Social Services Department became obstructive when residential provision was requested for my son. The request was turned down – they said it was not necessary at that time (my son was 20 years old). The decision was overturned by my son making a legal challenge.”* (Parent)

### Poor information, little choice

Gaining access to services relies on **sound information** for carers and accessible information for the adults themselves. And yet only 19% of adults have had any sort of **advocacy**

support to make their own feelings known about their choice of care, housing and other activities. Whether because of a lack of understanding about autism and Asperger syndrome on the part of the practitioners involved, or a lack of provision of information on local services, families find it tough to get information. 58% found it difficult to get information on adult services and what to expect in adulthood.

*“The main services lacking are financial and housing support and guidance of what he is entitled to.”* (Parent)

*“I have considerable difficulty with knowing who to contact in social services and who would be responsible for the particular services required.”* (Adult)

Similarly, over half of those with a transition plan (51%) were still unclear about what they would face in adulthood. 70% of those with transition plans did not feel their children understood the process or implications for their adult life. Independent advocacy was only offered to 9% of people through the transition planning process.

*“I have found that the lack of liaison between all organisations and agencies, even for information, is a great problem.”* (Parent)

**I**nclusion is the fourth key principle in the Learning Disability White Paper:

*‘Being part of the mainstream is something most of us take for granted. We go to work, look after our families, visit our GP, use transport, go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.’*

A popular misconception is that all people with autism dislike social contact and enjoy solitary activities. Two thirds (65%) of parents said that their sons and daughters have difficulties **making friends**. For those in their teens this was 74%. Only 7% of the families surveyed believed that their son or daughter had no need of friends.

*“He would love a girlfriend – I just want to cry – it breaks my heart.”* (Parent)

Over 80% of adults said that their parents or family were the most important people in their life, and over half said their parents (mostly mothers) were the people they would most likely talk to if they had a problem.

*“His so-called friends use him, borrow or steal things from him. Using his computer skills – he is capable of putting together computer parts and mending machinery as well as using it. There is a history of homeless people moving in uninvited and stealing from him.”* (Parent)

*“I often end up talking to the wrong people.”* (Adult)

People with autism and Asperger syndrome find it difficult interacting with others and making friends. As a result many find themselves excluded socially. Almost a third (31%) of adults with autism or Asperger syndrome are involved in **no social activities** at all. This was higher for those in their teens and those with Asperger syndrome, both at 37%.

The survey of more able adults found that over a third go out only ‘rarely’ to any social event, and half will only go out once or twice a month. Parents confirmed this: 82% said their son or daughter has difficulty taking part in social activities. This figure was even higher for those in their teens and 20s.

*“He cannot go out alone. He has no friends. He is jeered at in public sometimes.”* (Parent)

*“Most of her friends are from clubs for the disabled. She has no friends from wider social groups. She doesn’t have anyone who could be described as a really close ‘best friend’.”* (Parent)

Given the difficulties of social interaction and behaviour and consequent social exclusion, people with autism spectrum conditions need support with these basic skills. And yet in transition planning only 25% felt that strategies to enable their child to take a full part in the community had been taken into account. Similarly, only 49% have had their social, recreational and leisure needs considered through their community care assessment. Initiatives which could benefit people with autism spectrum disorders include social skills training and more informal social groups.

*“He himself would like friends of his own age but apart from a support group meeting every two months he does not have much of social life. I pay for a support worker to take him on social outings.”* (Parent)

**Social groups** for people with autism and Asperger syndrome are usually facilitated by a support worker. They aim to tackle the problems people have with social interaction by getting together a group of friends and going out. Many of the activities that people with autism or Asperger syndrome do take part in tend to be structured: sports clubs (such swimming, badminton, cycling, rambling); pub activities (such as pool, skittles, dominoes), youth clubs and church activities. Typical events for a social group might be an evening at the pub, tenpin bowling, a concert – the normal sort of things

people do to relax. However only 28% of people surveyed had access to this type of social group, although 71% of parents thought their sons and daughters could benefit from them.

*“I think he would like more friends who don’t have any sort of disability. When he is out with them other people can be nasty.”* (Parent)

**Social skills training** is intended to provide people with a better understanding of their social difficulties and to foster more appropriate ways of dealing with these. They aim to improve conversational skills but will also encourage greater independence in areas such as work and living arrangements.

72% of parents said their sons and daughters had behaviours which others find unusual or anti-social: odd physical movements (such as rocking or hand flapping), repetitive or obsessive speech, inappropriate conversation, rituals, hyperactivity, talking loudly. 82% of parents believed their children would benefit from social skills training but only 44% had received any.

*“The careers service arranged a ‘life skills’ course which prevented him from stagnating at home.”* (Parent)

*“She needs continued social skills training to enable her to keep a job, if and when she finds one. She also needs on-going training in personal care and in the organisation of time. (She would stay up all night, if not prompted to go to bed).”* (Parent)

Ignored or ineligible?

**T**he impact of the failure of statutory authorities to provide adequate levels of support is devastating. Parents become lifelong carers, families break up, and mental ill health is too often a consequence both for the adult with autism or Asperger syndrome and for their carers as a result of their social exclusion.

*“Our marriage suffered and is still not right. I can understand why so many parents of autistic children are divorced.”* (Parent)

## Social exclusion of families and carers

Having a child with an autism spectrum condition has a huge impact on the whole family. In many cases families are excluded from ‘normal’ life. They suffer major disruption – any family social life (including holidays) is destroyed: one parent often has to give up their career to care for that child (then adult), siblings are neglected, marriages torn apart – the emotional stress is extremely damaging.

*“We’ve had major disruption to family life for 16 years. Injuries to family members, especially parents. Parents’ social life destroyed for 16 years. Severe limitations on where to go for holidays and what to do. Major reduction in family income (halved) due to one parent having to be at home all the time.”* (Parent)

*“It’s rendered the family dysfunctional and under great strain. External contact became very difficult due to my son’s behavioural problems.”* (Parent)

*“Our other daughter left home at 16 as she wanted to get away from these problems.”* (Parent)

*“We both got very distressed and depressed. His mother ended up on anti-depressants as a result of both the problems over his future and the sudden loss, at the same time, of all respite care.”* (Parent)

*“We have not had a holiday alone since our son was born. Where we go, he goes.”* (Parent)

This survey reveals that the burden of care extends well beyond the normal expectation of caring for a son or daughter at home. Half the adults are still living at home, and many parents reported their fears as to what will happen to them when they (the parents) become too old or too frail to continue to care for their son or daughter.

*“We are making no progress. Although the situation is tolerable we continue to be 24 hour carers with no breaks. Obviously this will not be possible to continue as we get older and we worry about the future for our son.”* (Parent)

## Mental ill health

A third (32%) of parents said their son or daughter had already experienced mental ill health – and where diagnosis was late this rose to 45% of those diagnosed in their 20s, and 50% of those diagnosed after the age of 30.

*“My son was not diagnosed with Asperger syndrome until he was 23 years old. He became very, very anxious, lonely, depressed, angry, worried why he was different and worried about his own future.”* (Parent)

*“Misdiagnosis and mistreatment led to a wasted seven years.”* (Parent)

Of those experiencing mental ill health, 56% suffered with **depression**, a further 11% suffered nervous breakdown or near **nervous breakdown**, and 8% felt suicidal or had attempted suicide.

*“Tried to overdose (twice). Slashed wrists (three times). Thankfully this phase seems to have passed.”* (Parent)

*“Because his problems were not taken seriously, he ended up at 13/14 becoming suicidal and having a breakdown. Earlier support might have avoided this.”* (Parent)

*“The delays were in the GP taking us seriously, to the extent that our son’s health was further impaired to him injuring himself and considering suicide.”* (Parent)

*“Catastrophic – he changed from the little lad who could tell you about space and Thomas the Tank Engine into someone too scared to speak.”*  
(Parent)

*“It’s blighted his life – he now has nothing.”*  
(Parent)

The **effects on the family** were equally serious: 30% of parents (unprompted) said that delays in diagnosis and services placed great stress on the whole family, and 23% said there was disruption to their family lives

*“The mental and physical health of all members of the family suffered, including our autistic child. The family was on the verge of breakdown when Social Services finally gave in.”* (Parent)

*“I became depressed too and ended up on anti-depressants. Work went by the board for a couple of years, as did our social life. Family life revolved around his problems and getting him back on his feet for many months. His younger brother found it very difficult, especially the severe anxiety which led to temper outbursts – shouting, swearing, hitting out. I used to find him in bed crying through fright and sadness for his brother.”* (Parent)

*“We cannot move on in our lives and we have no time for ourselves. We are also carers for very elderly parents.”* (Parent)

*“Enormous – extreme pressures – divisions – friction. My depression.”* (Parent)

*“Stress: mother now has chronic fatigue syndrome. Father off work with stress. Son isolated and heavily depressed.”* (Parent)

*“My doctor volunteered the opinion that the stress I have gone through has contributed to the heart attack I had two years ago.”*  
(Parent)

## Financial consequences: cost or benefit?

Independent living and employment were cited as major barriers for adults at the higher functioning end of the autism spectrum. According to the survey findings 37% of the respondents with higher functioning adults who answered the question on independent living (24% of the total sample) said that their son or daughter could live independently with only a few hours support each week. 4% are already living independently, and 13% with some professional or family support. In the adult survey over 80% of these more able adults who are not currently in any paid employment said they wanted to be. The number of people in the UK estimated to have high functioning autism or Asperger syndrome is 207,500, of whom 160,100 are adults.

Using the above figures:

- 59,237 adults *could* be living independently with only a few hours support each week
- 27,217 *are actually* living independently (either fully, or with some professional or family support)
- Therefore 32,020 are *capable* of living independently with a few hours support each week but are not doing so at the moment.

Only 12% of adults with Asperger syndrome are in full-time paid employment, and only 6% in part-time employment.

The average lifetime cost to the State for a person with high functioning autism is reported to be £785,000 (Knapp and Jarbrink 2001).

The financial argument for supporting these 32,000 adults into employment and independent living is compelling: this survey indicates that it could save the Government up to £25 billion over the lifetime of those individuals.

## Ignored through ignorance or ineligible for Inclusion?

**A**utism spectrum disorder is a complex and challenging disability which is not recognised adequately by those statutory agencies responsible for providing diagnosis and services, whether by ignorance or design.

The medical terminology ‘high’, ‘medium’ or ‘low’ functioning autism is not an indicator of the individual’s ability to live an independent life. An understanding of language and an above average IQ can mask high levels of vulnerability and need.

Diagnosis (in particular, early diagnosis) is key to accessing appropriate services. This survey shows that delays in receiving a diagnosis are all too common, and frequently devastating for both the adult with autism or Asperger syndrome, their carers and families. Deteriorating mental health leading to the need for acute services is a frequent occurrence.

Autism and Asperger syndrome do not fit into the eligibility criteria operated by many local authorities. Consequently many people are being discriminated against, falling through gaps in the system created by unhelpful boundaries and definitions and a marked lack of responsibility from the agencies who have a duty to them.

Many local authorities are routinely failing to carry out their statutory duties towards people with autism and Asperger syndrome:

- failing to conduct transition planning from children’s services into adult provision; and
- failing to carry out community care assessments for the majority of people with autism and Asperger syndrome;

- failing to provide an appropriate range of services and provision to meet the needs of people with autism and Asperger syndrome, the majority of whom are unidentified and vulnerable.

Services are driven by budgets. Eligibility criteria are constantly tightened in order to control expenditure. As a result thousands of people with autism and Asperger syndrome are excluded from the help and support they need – support and services which are theirs by right.

As a result, the burden of responsibility – both financially and personally – is shouldered by parents and carers.

Part of this can be attributed to widespread ignorance of the needs of people with autism and Asperger syndrome, and a lack of expertise in the care and management of people with autism spectrum disorders. Better training is undoubtedly required.

But most of all this survey throws into sharp relief the lonely, lengthy and confusing battle for services which faces people with autism and Asperger syndrome, and their carers, at the transition from childhood into adulthood. The Government policy of inclusion within the education system is raising expectations which are only shattered in adulthood as current provision is woefully inadequate. The crucial years of transition can mean the difference between an unhappy and dependent existence in adulthood, or a more independent and fulfilled life.

*“It’s devastating. None of us can live a normal life. The stress is intolerable. It would have been nice to have had some support, but we have had none.” (Parent)*



**T**he National Autistic Society is calling on the Government to address the needs of people with autism spectrum disorders as a matter of urgency.

The Government should issue national guidance to all relevant agencies that clarifies their statutory duties and responsibilities to address the specific needs of people with autism spectrum disorders. This guidance must tackle these needs holistically at a national, regional and local level, and ensure effective and accountable joint working across all agencies, to achieve agreed objectives.

It should cover:

- Health services
- Diagnostic services
- Social services
- Education
- Housing
- Transport
- Benefits
- Employment
- Advocacy
- Forensic services
- Training of all relevant practitioners.

This guidance should be accompanied by a dedicated funding stream, conditional upon multi-agency collaboration. This guidance should be widely promoted and made accessible, for example through a national conference and a dedicated website.

## Detailed Recommendations

There are specific recommendations for a wide range of agencies which this survey has raised. They are as follows:

### Local Government and Health

- Local Authority Community Care Plans should identify the lead agency to be responsible for identifying people in their area with autism and Asperger syndrome, and co-ordinating their care. The respective roles and responsibilities of health, education and social services should be clearly defined and published in an accessible format for people with autism and Asperger syndrome

and their carers. We would anticipate that the proposed 'Care Trust' have considerable potential benefit for improving co-ordination and responding to need.

- Local Authorities and health authorities should identify a senior manager with overall responsibility for services for people with autism or Asperger syndrome.
- Tailored services for people with autism and Asperger syndrome should be a strategic priority of Commissioners within the Local and Health Authorities. This must include an increase in the number of autism-specific and autism-friendly day care places available, and residential or supported living placements as appropriate according to level of need.
- Local Authorities and Health Authorities should establish protocols for sharing information about individuals with autism and Asperger syndrome in their area.
- Local Authorities should co-ordinate joint-agency support and training for practitioners in education, mental health and learning disability services who are required to meet the needs of people with autism and Asperger syndrome in their area.
- Local Connexions Partnerships (where available) should be responsible for overseeing the transition of all young people with autism and Asperger syndrome in their area, from education, into further or higher education, employment, or adult services.
- S. 19 (2) of the Children Act 1989 places a statutory duty on Local Authorities to work with the Local Education Authority to meet the needs of disabled children in their area: this should include the establishment of an outreach team (in conjunction with Connexions Personal Advisers) with responsibility for making transitional arrangements for individuals with an autism spectrum disorder between the ages of sixteen and nineteen. This team should support such individuals to enable them to access and

Ignored or ineligible?

benefit from appropriate services, taking into account their social and life skills. The outreach team should develop a transition framework for use by all relevant agencies.

- Local Authorities should provide all information on services for people with an autism spectrum condition in formats which are accessible to both people with autism or Asperger syndrome, and their carers.

## Social Services Departments

- Social Services Departments should ensure that all people with autism and Asperger syndrome, and/or their families in their area are made aware of their entitlement to, and receive, a needs-led assessment within the terms of the NHS and Community Care Act 1990. This should be carried out by a multi-agency team, specifically trained to assess the needs of a person with autism or Asperger syndrome. The person concerned should receive an accessible version of their care plan, with full explanation. The local authority should ensure that the plan is implemented in full.
- All adults with autism and Asperger syndrome should have access to an independent advocate during the assessment process to ensure that they can access and influence the planning of their care.
- Social Services departments, in conjunction with local health authorities, should develop a range of services, including individual and group-based social skills training, social groups, and individual counselling, in order to meet the needs of adults with autism and Asperger syndrome, and their families, living in their area.
- A specialist Social Worker (Care Manager) should be identified in each local authority with responsibility for overseeing the referral and care of individuals with autism and Asperger syndrome for services. He/she would be responsible for the following:
  - Co-ordinating multi-disciplinary teams to assess the needs of people with autism and Asperger syndrome in their area, and

provide them with the necessary home-care services, transport arrangements etc.

- Liaising with housing associations and other agencies to develop appropriate accommodation for people with autism and Asperger syndrome.
  - Identifying areas of unmet need for development of services.
  - Providing autism-awareness training for relevant departments and agencies, in order to ensure that all staff who come into contact with people with autism and Asperger syndrome have some training in the field
  - Ensuring that services, if not autism-specific, are at least autism-friendly. (This should avoid difficulties, reduce out of county placements, and the need for acute services later on.)
  - Developing and supporting the delivery of a social skills development programme for individuals with Autism and Asperger syndrome in conjunction with an identified provider.
  - Carers of adults with autism and Asperger syndrome should be made aware of their entitlement to a carers assessment within the terms of the Carers and Disabled Children's Act 2000, and appropriate respite services should be made available – including befriending schemes (in partnership with the voluntary sector) to offer social opportunities and short-term respite services.
- ## Education
- The Local Education Authority should plan strategically for training all teachers, learning support assistants, special educational needs coordinators and educational psychologists who work with people with autism and Asperger syndrome.
  - The involvement of all relevant agencies within the transition planning process must be enforced. Each plan must address the current and future educational, social, emotional, housing, transport and other needs of the individual concerned, and must be regularly reviewed.

- Through the transition planning process young people with autism and Asperger syndrome and their parents should be informed of their right to a Community Care Assessment.
- The national training programme for Connexions personal advisers should incorporate an autism awareness component.

## Housing

- More able people with autism or Asperger syndrome should not be offered a house or flat unless there are arrangements for support where this is deemed to be appropriate. The NHS and Community Care Act 1990 requires Housing and Social Services Departments to work together to make appropriate arrangements. Article 8 of the Human Rights Act emphasises the right to home and family life, frequently denied to people with autism spectrum disorders.
- Housing and Social Services Departments should work together to ensure the provision of a range of cost-effective and flexible housing solutions, to accommodate the needs of people across the entire spectrum including:
  - Appropriate residential care placements
  - Clustered flats and bedsits – where small groups of individuals with autism and Asperger syndrome live in self-contained flats, with a support worker, who can be called upon to assist with difficulties that arise
  - Sheltered housing – a mixture of shared or self-contained flats: some could be monitored by a warden with individualised outreach support provided
  - Tenancies and shared equity schemes, including supported housing projects.

## Health and Diagnostic Services

- A national strategy of training should be developed for all primary care practitioners, health visitors and mental health professionals in identifying autism spectrum conditions.
- Adult psychiatrists in particular should be targeted for training to expand their expertise in developmental disorders. This will avoid the

treatment of people with autism and Asperger syndrome for acquired conditions such as mental health problems without reference to their underlying diagnosis.

- A national protocol for the screening and assessment of autism spectrum disorders should be established.
- Young people with autism or Asperger syndrome who are in paediatric services should be given a health transition plan, drawn up in conjunction with adult health services to ensure continuity of care.
- Many individuals with Asperger syndrome currently experience difficulty in having their needs recognised by any agency until their social and lifestyle difficulties bring them to the attention of psychiatric services. The identification of people with autism and Asperger syndrome therefore needs to be a priority for Social Services and health.
- Mental Health and Learning Disability services must have the necessary expertise to undertake assessment, and provide the earliest diagnosis of, and advice to, people with autism or Asperger syndrome in order to avoid onset of mental health problems.
- The establishment of regional diagnostic centres, offering a quality diagnostic service and acting as a resource for data collection should be a priority.
- People with autism and Asperger syndrome should be ensured access to specialist psychotherapy and counselling services.

## Employment

- A Government strategy to promote the employment of people with autism and Asperger syndrome should be drawn up in consultation with potential users of this service and with the National Autistic Society's *Prospects* employment consultancy.
- The Government should ensure that people with autism and Asperger syndrome are

Ignored or ineligible?

reached through the New Deal for Disabled People.

- The Government should ensure that people with autism and Asperger syndrome throughout the UK have access to appropriate Employment Service programmes, such as *Work Preparation* and *Access to Work*. These schemes are only currently available in London, Sheffield and Glasgow for people with autism spectrum disorders.
- Local authorities should devise strategies, in conjunction with their local Employment Service, for the development of appropriate supported (or otherwise) employment schemes for people with autism and Asperger syndrome in their area.

## What is autism?

**A**UTISM is a lifelong and complex developmental disability that affects the way a person communicates and relates to people around them. The condition varies from person to person; some people with the condition may also have accompanying learning difficulties, while others are much more able with average or above average intelligence. Similarly, linguistic skills range from those who are mute to those who display complex, grammatically correct speech.

Autism is found in every country and region of the world, and in families of all racial, ethnic, religious, and economic backgrounds. Emerging in childhood, it affects about 1 in 110 people and is between four and fifteen times more common in boys than girls. Girls with the disorder, however, tend to have more severe symptoms and lower intelligence. In addition to

loss of personal potential, the cost of health and educational services to those affected costs at least £1 billion each year (Knapp and Jarbrink 2001). So, at some level, autism affects us all.

Everyone with the condition has difficulty with **social interaction, social communication and imagination** – the **triad of impairments** (Wing and Gould 1979). These are generally accompanied by a narrow, repetitive range of activities.

People with **Asperger syndrome** are at the more able end, and are the most numerous group within the autism spectrum. They are verbal, but their speech may be unusual, pedantic or stilted. Due to an impairment in spontaneous empathy they tend to work things out intellectually. Many people with Asperger syndrome have interests not shared with others. Though some prefer to be alone, as adults, many are highly motivated to ‘fit in’ and do not look odd.

### Prevalence rates

People with Learning Disabilities (IQ under 70)	Approx. Rate Per 10,000
Kanner Syndrome	5
Other spectrum disorders	15
<b>Total</b>	<b>20</b>
People with average or high ability (IQ 70 or above)	
Asperger Syndrome	36
Other spectrum disorders	35
<b>Total</b>	<b>71</b>
<b>Total estimated prevalence rate</b>	<b>91</b>

Ignored or ineligible?

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