The Impact of Autism

A report compiled for the
All Party Parliamentary Group on Autism

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INTRODUCTION

People with autism and Asperger Syndrome can make a significant contribution to society, as well as to their families and those close to them. However, having autism is generally disruptive and difficult for the person themselves and their family, and often involves great financial sacrifice.

The impact of autism also extends far beyond a person's immediate family. This report will demonstrate the far-reaching cost implications of the disability, and will illustrate the significant impact upon society currently caused by autism.

The report will also demonstrate that the introduction of some interventions is beneficial, not only in human terms, but also in cost-cutting terms. The report includes a series of recommendations for future action. These have been proposed by various autism organisations, parents of people with autism, people with autism and professionals.
PURPOSE OF THE REPORT AND EXECUTIVE SUMMARY

This study is intended as a preliminary comment on the effect of autism on society. It aims to point out those needs that may not be immediately obvious.

The evidence is gathered mainly by literature review, but also by personal correspondence with expert professionals, parents and people with autism and Asperger Syndrome.

A detailed report on the cost of autism was published in March 2001, by Krister Jarbrink and Martin Knapp. It was the first cost study in the UK to look exclusively at autism, hence the majority of information in this report is based on study of disability and learning disability in general, as there is very little published material available on costs and cost benefits specific to autism.

Knapp and Jarbrink reached an estimated figure of £1 billion annual total cost of autism in the UK, and an average lifetime cost per person with autism of £2,940,538

Krister Jarbrink has also devised a parents' questionnaire which will, he believes, demonstrate further hidden costs, making the initial estimate of cost too low. The questionnaire has not yet been implemented.

It must be emphasised that the aim of this report is NOT to suggest that autism is an intolerable burden, but rather to demonstrate that a few changes to national provision could considerably improve the quality of life for people with autism and their families. Often preventative costs will save expensive crisis management. People with autism can make a significant contribution to society, as families and professionals are quick to affirm, but often the support that they need to fulfil their potential is not available.

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1 Jarbrink, K and Knapp, M 'The Economic Impact of Autism in Britain' Autism Vol 5 No1 pp 7 – 21 March 2001, Sage and NAS
Areas of Impact which will be covered in the report:

For each of the areas identified there are a series of recommendations proposed by autism organisations. More detailed recommendations can be found in the main body of the report.

Prevalence. The whole report is set against the backdrop of the prevalence of autism. There are no clear national numbers for the prevalence of autism, and until there are it will be very difficult to plan resources. The need for clear national numbers is particularly important given that there is great concern that autism might be increasing.

Recommendations for Prevalence

- the establishment of a national register of people with autistic spectrum disorder
- the need for joined up thinking and services across LEA’s, Social Services Departments and Health Authorities at local level, and Whitehall departments at government levels to ensure diagnosis and service provision

The Family - including the ‘hidden costs’ of care for families caring for both children and adults; the shortfall in benefits; loss of employment; and relationship costs.

- The report demonstrates the type of additional costs for a family caring for either an adult or a child with autism, some of which are considerable.
- It shows the shortfall from benefits, and will show how family carers are subsidising the Community Care budget.
- It also shows that caring has an ‘opportunity cost’, in that carers are often unable to work and so cannot contribute to society.
- There are additional medical costs for carers, for whom the stress of caring often affects their physical and emotional well-being.
- There is also the cost of households dividing, when autism takes its toll on relationships.
- There is a lack of childcare and respite or short term breaks for carers.
- There is a disappointingly low take-up of direct payments, which allow people to take control for their own care. This suggests a difficulty in access of direct payments.

Recommendations for the Family

- need for further support for families, both emotional and practical
- benefits need to take the additional expenditure for people with autism into account
- GPs and others need to be more aware of the strains on relationships, and need to refer on for further support

The Education Service - from the cost implications of early years intervention to the lack of investment at transition stage.

- There are a variety of different costs involved depending on the type of education needed.
- Some children will require autism specific special schools, whereas others will thrive in the mainstream, or in other types of special schools.
• There are hidden costs in the lack of suitable provision, in that there are children who have
to be excluded from school, and others who remain at home because adequate provision
could not be found for them.

• Difficulties in provision are reflected in the high number of tribunals for children
with autism

• There is more investment needed in training. Many teachers have not had autism specific
training, which could be partly responsible for the amount of tribunals for people with
autism.

• Intensive early intervention programmes are very costly, but there is some research
evidence to suggest a cost benefit in later years. There is further research going on into
the level of intervention needed, and the ultimate cost benefit.

Education Recommendations
• early intervention can only be achieved by early identification – the need for the national
adoption of the CHAT
• the need for more training for teachers and parents
• the need for flexibility in inclusion policies e.g. after school socialising for children who
would not manage in a mainstream school
• the need for careful transition planning at each move through the education process, and
particularly at the transition to adult education

Social Services - residential and day care costs, and the implications of charging.
• For adults who require ongoing support, residential homes, though more expensive than
the traditional long stay hospitals, have been found to be considerably more beneficial for
people.

• At the other end of the scale of need, people who need some low-level, relatively low-cost
support, such as modest home care and social skill training, are often completely excluded
from help until they reach a crisis such as a deterioration of their mental health.

• Crisis intervention is far more expensive than any low level support which could have
avoided this.

• In addition, some people have found that they have had to refuse care when Social
Services charges were unaffordable.

Social Services Recommendations
• the need for pooled local budgets, in the form of specialist area teams
• a national protocol for placing people with Asperger syndrome under an
appropriate team
• the need for autism awareness training amongst social services staff
• a review of charging policies
• a more frequent and imaginative use of direct payments

The Health Service - including the costs of health care professionals; the unnecessary cost of
inappropriate medication; and hidden additional mental health problems.

• Diagnoses are difficult to get, and people are often not picked up at an early stage.

• The problems often worsen if the diagnosis is not made early, and people have their needs
misunderstood.
• There are problems with mental health problems accompanying autism and, conversely, people having their autism misdiagnosed as a mental health problem. Money is often wasted on incorrect treatment.
• Autism research is still at its early stages

Recommendations for Health
• government departments need to embrace the work of NIASA (National Initiative on Autism, screening and assessment)
• training for all health care professionals to ensure all primary health care professionals are aware of autism
• adoption of a code of practice for administering medication for people with autism
• an increase in research on causes of autism

Eligibility criteria and the cost of ‘falling through the gaps’ - including lost revenue from employment, and impact on the criminal justice system.

• There is a great disparity between the number of more able people with autism and Asperger syndrome in the general population, and the number receiving a service. Few people had a Community Care Assessment, and of those that did only 45% were receiving services specified in the assessment.
• There are a small number of people in the criminal justice system with their needs not recognised, therefore, there is a waste of resources because of the ‘revolving door effect’.
• Where employment support is given, there is a cost benefit. Not only do people with Asperger syndrome benefit from contributing to society, an initial study has suggested a cost benefit through the reduction in reliance on benefits.

Recommendations to avoid ‘falling through the gaps’
• the need to identify a clear service niche for people with autism, particularly those who are more able
• the need for multi-agency planning for people with autism and Asperger syndrome in special hospitals
• further research into autism prevalence in the general prison population
• an increase in employment support, to enable people with autism to contribute their many gifts to society

Overall Conclusion
In conclusion, whilst there is the need for more financial outlay for people with autism, it has been demonstrated that preventative work to avoid crises for individuals with autism and their families can save money in the long term, and enable people with autism to achieve their full potential.
Note on the Autism Spectrum and Prevalence

Autism is an ‘umbrella’ diagnosis that covers a very wide range of abilities. This report will discuss a range of difficulties and possible interventions, some of which will be more appropriate for less able people on the autistic spectrum, and others which would meet the needs of more able individuals with autism and Asperger syndrome. The report will demonstrate that those with higher abilities often fail to receive the necessary help, because their needs are not easily classified. As a result they often miss the opportunity to develop their full potential in society.

Prevalence

A major difficulty in compiling a report of this type is that there are no accurate figures on the national prevalence of autism, and there is currently no requirement for health or education services to record new diagnoses.

The only figure available at present is that estimated by The National Autistic Society, which combines two studies. The first of these was conducted by Wing in 1979. It identified a prevalence rate for those with autism and accompanying learning disability as approximately 20 in every 10,000 children. A 1993 study in Gothenburg by Ehlers and Gillberg found a prevalence of high functioning autism and Asperger syndrome of 36 per 10,000, and another 35 per 10,000 with social impairments which fit into the autism spectrum. The two studies are combined to estimate prevalence of autism spectrum disorders in the United Kingdom at 91 per 10,000 head of population, or 1 in 110.

Recent smaller scale studies have confirmed this - for instance Dr. Fiona Scott et al (Cambridge Autism Research Centre) conducted a survey of 5-11 year olds in Cambridgeshire (over 34,000 children). They found a prevalence rate of 1 in 175. Scott found 12.5% of the special needs population had diagnoses of autism spectrum disorder and about 50% of mainstream primary schools have at least one pupil with an autism spectrum disorder.

In the absence of a national recording system it is impossible to confirm the local observations on a national level. Dr. Fiona Scott points out that if her figures are translated nationally around half a million people suffer from Autism Spectrum Disorder, which has enormous implications for families, schools, and services.

There is increasing concern in some areas of autism research that autism has dramatically increased over the last ten years. Anecdotally paediatricians, teachers and others are reporting far more cases, which has been given some support by research – this is acknowledged by the Learning Disability White Paper, which mentions: “a sharp rise in the reported numbers of school age children with autistic spectrum disorders”.

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2 Defined by a triad of impairments – profound difficulties with social interaction, communication and imagination.
4 Dr. Scott presented the findings of her research to the All Party Parliamentary Group in May 2000.
However, current inadequacy in data collection was illustrated in a survey of Health Authority records on autism, which indicated that only 17% of respondents (52% response rate) had detailed data on autism.\textsuperscript{6}

**PREVALENCE - RECOMMENDATIONS**

- Local Authorities and local health services should be required to record cases of new diagnoses of autism and devise protocols for sharing this information. This would allow for services to be targeted more effectively, and would be in keeping with the Government's commitment to 'joined-up thinking' across agencies.

- Furthermore, this local information should be collected centrally, to create a national database.

- An alternative approach to determining prevalence, which could run in tandem with a national register, would be a cohort study following a particular age group through into adulthood.\textsuperscript{7}

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\textsuperscript{6} Thrower, D (2000) *Local Monitoring by Health Authorities of Childhood Autism Incidence in the UK*. Warrington

\textsuperscript{7} This was the most common conclusion reached by a variety of research experts in the field, in response to a consultation conducted by Dr Stephen Ladyman MP, Chair of the All Party Parliamentary Group on Autism.
1. IMPACT ON THE FAMILY

Families of people with autism often struggle with the emotional and physical effort of living with someone who may have complex and challenging behaviour\(^8\), leading to lack of sleep, and a significant degree of social exclusion.\(^9\) This is commonly exacerbated by a 'battle' with professionals for diagnosis and services. These difficulties are often accompanied by significant financial costs.

1.1 The Additional Costs of Caring for a Child with Autism

A survey of more than 1,100 families of children with severe disabilities found many had additional weekly costs.\(^10\)

These included:

<table>
<thead>
<tr>
<th>Medical consultations/ treatments</th>
<th>Treats for the disabled child</th>
<th>Bedding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special equipment for child</td>
<td>Treats for other children</td>
<td>Replacing furniture/carpets</td>
</tr>
<tr>
<td>Toiletries/medical supplies</td>
<td>Holiday</td>
<td>Repairs to home/furniture</td>
</tr>
<tr>
<td>Therapies for child</td>
<td>Adaptations to home</td>
<td>Transport costs</td>
</tr>
<tr>
<td>Hospital visiting costs</td>
<td>House moves</td>
<td>Telephone bills</td>
</tr>
<tr>
<td>Help with housework</td>
<td>Heating</td>
<td>Extra lessons for child</td>
</tr>
<tr>
<td>Childminding/babysitting</td>
<td>Food</td>
<td></td>
</tr>
<tr>
<td>Keeping child amused</td>
<td>Clothing</td>
<td></td>
</tr>
<tr>
<td>Outings/leisure activities</td>
<td>Washing/laundry</td>
<td></td>
</tr>
</tbody>
</table>

Some costs that are specific to autism can also be identified:

- Some families turn to **home education** programmes in the absence of other assistance for their pre school child. Some Local Education Authorities refuse to fund intensive early intervention programmes, and therefore families fund them themselves. An Applied Behavioural Analysis programme, such as the Lovaas programme, costs approximately £20,000 a year. Some families go to great lengths, such as remortgaging their homes, to pay for the teaching costs.

- Other families seek **biochemical tests** for their children, to determine whether their child has dietary sensitivities. These tests must be paid for privately. One clinic charges between £400 and £500 for a series of tests.

- Middleton and Dobson estimated these costs to amount to £141/week for a child with a severe disability. When compared to current benefit levels, this revealed a significant shortfall: "the average minimum essential cost of bringing up a child with a severe disability is £141 per week or a total of £125,000 from birth to 17 years. This is three times more

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\(^8\) This can sometimes involve injury to themselves or to other people

\(^9\) see for example Haywood, K (2000) Autism: a problem for the child or their parents? Honormead Schools, Derbyshire

than for a child without a severe disability”. Even if families received their maximum benefit entitlement, Middleton and Dobson calculated that there would still be a shortfall of between £30 and £80 a week, depending on different levels of disability and different levels of achievement.

The difference between the amount given to families to care for their child with disabilities, and the cost to the state, were the state to accommodate them, is striking:

<table>
<thead>
<tr>
<th>Type of cost</th>
<th>Estimated cost per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>The average estimated unit cost of a local authority children's home</td>
<td>£1,563 per resident week &amp; £1,782 care package costs.</td>
</tr>
<tr>
<td>Average estimated cost of foster care</td>
<td>£514 per child per week.</td>
</tr>
</tbody>
</table>

It is clear therefore that informal parent carers make a very significant saving to the Community Care budgets. However, the care provided by informal carers is often both financially unsupported, and at a personal cost (see 1.5).

- The introduction of carers assessments and direct payments in the Carers for Disabled Children Act, the extension of Disability Living Allowance for three and four year olds, and the disability income guarantee on top of Income Support were all welcomed by the representative organisations. However, they do not appear to go far enough to address the shortfall which has been demonstrated.

1.2 The cost of caring for an adult with autism

A study of people with Asperger syndrome in Avon found that 63% of adults are living with their parents, which amounts to a considerable saving to the community care budget in the extra care and support provided informally. The National Autistic Society found that 49% of adults with either autism or Asperger syndrome are still living at home with their parents.

Indeed, Mencap conducted a study of families caring for adult children with learning disabilities, and concluded that: “Families receive perhaps a quarter of what it would cost the State to provide fully for an adult with severe learning disabilities living away from home”. However, the report also observed that any calculations of the cost of caring to families would be inaccurate because families cut back and make savings as a matter of course.

Just under 70% of parents said that the benefits received were inadequate. This may suggest that approximately 30% of parents had adequate income. However, interviews showed that those who believed the money was enough were actually very careful not to overspend. The survey found generally that families have to decide which needs to forego, as they cannot provide for all needs.

13 Barnard, J, Harvey, V, Potter, D and Prior,A 2001 Ignored or Ineligible? The Reality for Adults with Autistic Spectrum Disorder NAS, London
14 Mencap Campaigns Department 1994 Paying the Price, London
Some families are further constrained financially by Social Services day care costs, which eat further into the small benefits income. The Mencap report showed that some families had been forced to give up much needed services because the costs were prohibitive.\(^{15}\)

1.3 Impact on Employment of carers

Employment has been found to have considerable psychological benefits for carers.\(^ {16}\) However, caring for a person with autism and Asperger syndrome commonly impacts on the carer financially, both in extra costs, and in their capacity to work.

"My wife gave up her teaching job in 1984, and we had always planned that she wouldn't start work again until the children were seven or eight years old. In fact, the difficulties of our situation and the lack of significant support from Social Services, mean that her return to work is not a practical or possible option. This has affected my own prospects, not only for career advancement, but my very job security. I would make the following points:

Carers who work extremely hard receive less than an unemployed person.
Carers in many cases receive less than the person they care for.
Carers have no industrial injury cover, despite the stress and physical exertion."

Father of two children with autism, aged nine and ten\(^ {17}\)

A survey of carers with a paid job and carers without found that, of those who worked, nearly three quarters said that their earnings were affected by caring.\(^ {18}\) Their average annual loss was £5,625. Carers without a paid job had an average annual loss of £9,763.

It is not just the individual caring families who are affected, however. There is a cost to society in lost labour of carers - ie the cost of lost contributions in the employment world by people who were caring for a family member - they found a 10% reduction in earnings capacity of those caring for 20 hours or more per week.\(^ {19}\)

Similarly, voluntary organisations that support people with autism and Asperger syndrome and their carers, such as the National Autistic Society, and Parents Autism Campaign for Education, report anecdotally that a significant proportion of families of children with autism are reliant on benefits, having given up their employment due to demands of caring for their child.

1.4 Childcare, after school facilities, and respite.

Access to work for carers is dependent upon the availability of appropriate child-care and respite facilities. However, parents of children with autism spectrum disorders report difficulty in accessing these services, and this difficulty has been highlighted by several studies on

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\(^{15}\) Ibid


\(^{17}\) Carers National Association, 1996 The True Costs of caring: a survey of carers’ lost income, London

\(^{18}\) Ibid.

respite\textsuperscript{20}. A local study on respite found that a third of respondents did not have any respite at all, and of those who did, 28\% were not satisfied. One parent commented: "Our last evening out was four years ago"\textsuperscript{21}

"At the Women Returners Seminar at the launch of Voices on the 9th of October with Baroness Jay and Tessa Jowell, to which I was invited, one of the speakers (a college organiser) in the later smaller group discussions, admitted that creche places were near impossible for the autistic child. By default therefore there is little access to college courses for mothers of autistic children". Quote from a parent.

Childcare during school holidays is often oversubscribed as the long summer holiday in particular causes prolonged stress to families. However, a typical autism-specific playscheme costs c. £30/day per child, with an additional cost of £20 per day to cover the costs of coordinators.\textsuperscript{22}

"I optimistically thought that I could just go off and find a job with a salary to put right the house defects caused by our lack of financial security during the years of our child being out of school (three in all). I am still having to be flexible and he is currently home mid-week. Where is the affordable childcare for the autistic child?" Quote from a parent

Families with children with autism do not have the breaks that other families would receive as a matter of course, such as nurseries or youth clubs. Most children are able to entertain themselves with minimal supervision after school, while families with a child with autism are obliged to continue the educational process, to keep working to generalise skills learnt during the day at nursery or school, adding to the effort of caring, and making appropriate childcare and respite harder to find.

Research by the Kids' Club Network highlights that there are still large gaps in provision of youth clubs for children with special needs - they identify that only 16\% of their clubs have children with disabilities attending.\textsuperscript{23}

In relation to adults, the advent of direct payments should mean providing the person with autism with activities they enjoy, with resources used to suit the individual, as well as providing flexible opportunities for respite for the carers. However, no organisation consulted could name any adult with autism and Asperger syndrome who was receiving direct payments to their knowledge.

1.5 The Stress of Caring

There are hidden costs in the cost to carers' health of the stress and sleeplessness frequently experienced by many families with children with autism. It is common for families to have severely disrupted sleep for years, as children with autism often have disturbed sleep

\textsuperscript{20} Eg Barnardo’s (1989) Barnardo’s Family Link Project: an evaluation of the service (Wales); Sharing the Caring: Respite Care for Children and Families NCH (1991); North East Essex Shared Care (1994) Respite Care for Children with Autism etc.


\textsuperscript{22} Personal correspondence with NAS regional office

patterns: “Autistic children appear to be especially prone to this problem, and in has been estimated that more than half exhibit some disturbance in sleep patterns. This suggests some form of deficit in the brain systems that normally promote sleep”. Many couples can only manage by a 'shift system' - one staying awake whilst the other sleeps.

Research has shown evidence of elevated levels of stress in mothers of children with autism, with stress levels in almost half of the sample within the 'critical range' of distress. The mothers experienced more symptoms of stress than parents of children with other disabilities such as severe learning disabilities and Down's syndrome, and parents of normally developing children. Carers may well find their general health is affected by the stress – for instance in a study on respite, 81% of respondents said they had suffered from stress as a result of caring for someone with autistic spectrum disorder.

Siblings are also affected, as much of the time and energy of parents is necessarily directed to the child with autism.

“It’s rendered the family dysfunctional and under great strain” (Quote from parent).  

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

Respite is often a lifeline for struggling families. Many local authorities offer foster carers to provide weekend breaks for children, however autism specific respite services are uncommon, and given the complexity of autism, foster carers need an understanding of autism and time to get to know the child. Similar respite schemes for adults with learning disabilities and autism are rarer, and often over-subscribed.

Stress levels inevitably impact on family relationships. It is widely accepted, anecdotally, that families with a child with autism are more vulnerable to marital breakdown. Apart from the personal tragedy involved, the consequence for society is such that often part of the family (typically mothers and children) will then be reliant on state benefits.

Research into families under stress has demonstrated a link between relationship breakdown and poor physical and mental health. People “are more likely to consult their doctor for almost all categories of illness and have relatively high consulting levels for infectious diseases, mental disorders, disorders of the respiratory system, skin diseases and accidents” following a relationship breakdown.

The evidence points ultimately therefore to a significant cost to the state in the stress placed on individual carers, and the consequent breakdown in health and family relationships.

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23 Panksepp, J 'Melatonin. The sleep master . An Emerging role for this over-the-counter supplement in the treatment of autism' Lost and Found: Perspectives on Brain, Emotions, and Culture www.autism.org/melatonin.html  
24 Brogan, C (2000), The Diagnosis of Children with autistic spectrum disorders: implications for parents, Glasgow Caledonian University  
25 Barson, C 1998 Autism: supporting the family NAS, Wales  
26 Barnard, J, Harvey, V, Potter, D and Prior, A 2001 Ignored or Ineligible? The Reality for Adults with Autistic Spectrum Disorder NAS, London  
27 Ibid  
IMPACT ON THE FAMILY - RECOMMENDATIONS

There may be a significant cost-benefit across Government agencies in the provision of support to struggling families who care for a child with autism. Such support can help to avoid home circumstances breaking down, medical costs which can result from stress and the costs of full time residential care when a family is no longer able to cope. Additional supports in place would go some way towards reducing family stress, the risk of relationship breakdown, the financial and personal burden on carers, while still offering some cost-benefit to the state.

- **Carers Support Grants** – Local Authorities should be encouraged to use grants to fund a range of autism aware respite services, including befriending schemes, and sibling support groups.\(^{30}\) Local Authorities should be encouraged to train foster carers in autism awareness, and establish more respite services for carers of adults.

- The use of **direct payments** needs to be encouraged through better awareness. Good practice examples of imaginative person-led services being put in place by social workers need to be shared.\(^{31}\)

- **Primary Care Groups** should provide training for all staff to recognise marital distress\(^{32}\) - so for instance, a GP would be trained to recognise relationship difficulties behind stress symptoms, to refer people to the necessary help.

- There is a clear need for more financial support for families who care for a disabled child, This should be built in to the government’s targets for reducing child poverty.

\(^{30}\) See Appendix for list of other helplines and support.


\(^{32}\) A study of marital breakdown identified a need for training for all health professionals to identify marital distress and refer people for support accordingly One Plus One (1999) *High Divorce Rates*, The Lord Chancellor’s Office, London
2. IMPACT ON THE EDUCATION SERVICE

2.1 Cost of Education
All children with autism will require some level of support in education. The need will vary widely with ability, from a few hours additional help within a mainstream setting to needing supervision from two carers in a residential setting.

Example of the average costs of a range of autism-specific education placements are set out below:\(^{33}\)

<table>
<thead>
<tr>
<th>Service Provision type</th>
<th>Cost per individual per annum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day school place</td>
<td>£25,000</td>
</tr>
<tr>
<td>Residential school – 5 day weekly boarder</td>
<td>£50,000</td>
</tr>
<tr>
<td>Residential school - 52 weeks per year</td>
<td>£95,000</td>
</tr>
<tr>
<td>Residential school – 52 weeks per year with 1:1 support</td>
<td>£130,000</td>
</tr>
<tr>
<td>Early Years parent course (NAS Earlybird)</td>
<td>£675</td>
</tr>
<tr>
<td>FE College day place</td>
<td>£21,000</td>
</tr>
</tbody>
</table>

Jarbrink and Knapp’s study estimated slightly lower figures, the annual cost being estimated as £30 000 for a residential school and £10 000 for a special school with day attendance.\(^{34}\)

- Those children with autism who succeed in the mainstream do so because they have a teacher and learning support assistants who are aware of their needs and possess an understanding of autism. There are, however, many cases of children struggling in the mainstream, and even being excluded, because their needs are not understood. Children inappropriately placed are often excluded from school, and the delay and search for alternatives is a clear waste of resources. Schools require both a flexibility in approach and resources to cater for children with autism spectrum disorders.

2.2 Training
Whereas teachers working with children with sensory impairments must have specific training, there is no such national training strategy for autism. Some Local Education Authorities (LEAs) offer some training, and some have established autism outreach teams which will provide advice for particular children. The majority of mainstream teachers however, have no experience of special educational needs teaching, and no awareness of autism. Furthermore, by no means all special needs teachers will have received autism specific training.

A study by Helps et al.\(^{35}\) investigated teachers’ views of autism and their training needs. The study sample was taken from both mainstream and special schools, all of which were known to have contact with children with autism. The findings were as follows:

- 70% of mainstream teachers had worked with children with autism spectrum disorders, but only 5% had specific training in their teacher training, and a further 5% had been on subsequent training days.

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33 List of average costs of placements provided by the National Autistic Society.
• In Special Schools 50% of teachers and 40% of other staff had received special training. Even the special schools figures reflect a large proportion of people who had worked with people with autism without training.

• 28% of teachers cited a lack of knowledge about autism.

There are some good local examples of training which could be copied nationally. For example, North Somerset LEA offer all teachers and Learning Support Assistants the option of a one day awareness course on supporting children with autism or Asperger syndrome, and in the Avon area there are two support groups for teachers working with children within the autism spectrum.

Many families report that the search for the right school for their child feels like a battle with the LEA. They often only receive the required provision after taking their case to a Special Educational Needs Tribunal. Tribunals for children with autism had a 360% increase between ‘96 and ‘99, and are now on a high plateau. Cases for children with autism are only second to the much larger group who have difficulties placed under the umbrella of ‘literacy’.

The Tribunal process is a time-consuming and expensive process. It costs families between £1,000 and £2,300 in legal costs and possibly more if it includes the payment for expert witnesses such as private educational psychologists. It is equally time consuming and costly for the LEAs. For families which feel that a residential school is the right option for their child, there is often a delay of several months whilst Social Services and Education departments decide what proportion of the overall fees should be paid for by education and social services.

2.3 Early Intervention

Whilst there has yet to be a definitive comparative study of the various different early interventions available, there is general consensus amongst professionals that early intervention is very important to help a child reach their potential, and in some cases can reduce the need for services later on. However, early intervention is often unavailable, and some parents have opted for home programmes as a result. Such intensive early intervention home programmes are relatively expensive, at approximately £17000 - £20000 per child per year. Cost benefit research into Early Intervention is underway.

Though education professionals are in agreement that early, intensive intervention greatly assists a child’s development, it can only be achieved with early diagnosis. Evidence shows that parents experience considerable delays in diagnosis. The average age of a diagnosis for a child with autism is 6 years, while for a child with Asperger syndrome the average age is 11.

36 Training courses are offered by the NAS, Birmingham University and others.
39 Figures provided by the NAS Education Advocacy Service
41 This research is being conducted by Prof. Patricia Howlin of St George’s Hospital, London. Prof. Howlin spoke to the APPGA in Dec. 2000.
A Cambridge research team headed by Dr Simon Baron-Cohen has devised a simple screening mechanism for use by GP’s and Health Visitors at the 18-month developmental check, called the CHAT (the Checklist for Autism in Toddlers). It is intended to flag up children who show signs of autism for subsequent checks and diagnosis. The CHAT has yet to be adopted by most health authorities.

2.3 Transition

Carefully planned transitions are essential for children with autism at every stage of the education process. In reality changes of school are often a hurried, rushed affair without a proper consultation process with all involved. A National Autistic Society report found that only 53% of those in the relevant age group had a transition plan in place. At the top end of the age range, there is often a dearth of support for young adults when they leave education. A positive local example, which should be adopted nationally, is that the main FE colleges in the Avon area have met to discuss best practice for 'exiting' college for students with Asperger syndrome, so that they are not left abandoned at the end of their courses.

IMPACT ON EDUCATION – RECOMMENDATIONS

- All Primary Care Groups should be required to adopt the CHAT, in order to identify children with autism as early as possible.
- Forthcoming guidance for the Early Years Development and Childcare Partnerships should promote the use of CHAT and autism awareness.
- LEA’s must provide a range of educational provision for children with autism and Asperger syndrome.
- The government should establish a national training initiative, with ringfenced funding from the Standards Fund. Whilst there would be a cost involved, a greater awareness of the needs of someone with autism would reduce the risk and cost of exclusion, or of parents going to tribunal.
- Parents should be included in training, and given instruction in how to reinforce their child’s education at home, such as in the EarlyBird scheme.
- Transition should be a carefully structured, multidisciplinary process (as is intended but rarely happens)

3. IMPACT ON SOCIAL SERVICES

In addition to that care provided by families, many people with autism require lifelong support from care professionals. This has a considerable cost to Social Services.

3.1 Residential Costs

Over the last fifty years or so residential care has changed from long stay hospitals to small group homes in the community.

The Department of Health commissioned a study to cost supported living schemes for people with learning disabilities. It found:

<table>
<thead>
<tr>
<th>Type of Provision</th>
<th>Cost per annum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large group homes</td>
<td>£50,87330</td>
</tr>
<tr>
<td>Small group homes</td>
<td>£53,847</td>
</tr>
<tr>
<td>Supported living schemes</td>
<td>£57,076</td>
</tr>
</tbody>
</table>

The National Autistic Society quotes average costs of autism specific placements as:

<table>
<thead>
<tr>
<th>Type of Provision</th>
<th>Cost per annum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Care placement</td>
<td>£17,000</td>
</tr>
<tr>
<td>Residential and day care place (52 weeks a year)</td>
<td>£60,000</td>
</tr>
<tr>
<td>Residential and day care place (52 weeks a year) with 1:1 support</td>
<td>£90,000</td>
</tr>
</tbody>
</table>

A study by Haycox found that cost in itself was not measure enough, rather cost-benefit needed taking into account. His study comparing different types of community care homes found that, like Emerson, the larger group homes were cheaper to run, however: "the cheaper the type of community care utilised then the lower will be the corresponding quality of life experienced by clients". This is in line with the government thinking on Best Value - the key feature of which is that the quality of service, as well as its cost, matters.

The danger of 'short term economics' by Social Services was pointed out in a survey of parents: "Some parents believe the Social Services may veer towards the cheapest service option, which in the long run is uneconomical because it means the person has several placement breakdowns, and becomes increasingly difficult to place".

The advantages of community residential care, compared with the previous model of long-stay hospital care, are documented by Emerson. Emerson et al found that a £6000

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46 "Best value for these purposes is described as securing continuous improvement in the exercise of all functions undertaken by the authority, whether statutory or not, having regard to a combination of economy, efficiency and effectiveness" Local Government Act 1999
additional cost of providing care in the community rather than hospital care brought with it:
a 46% decrease in the rated level of institutional practices;
• a 52% decrease in the use of anti-psychotic medication;
• a 31% increase in staffing ratios;
• a 14% increase in the rated quality of internal planning procedures;
• a 19% increase in the rated homeliness of the setting;
• a 350% increase in access to independent advocacy;
• a 27% increase in the rated amount of choice available to residents;
• a 55% increase in the size of people’s social networks;
• a 350% increase in social integration;
• a 32% increase in the number of hours per week of scheduled day activity;
• a 134% increase in the number of recreational or community-based activities;
• a 96% increase in the variety of recreational or community based activities.

The residential costs quoted above are the total costs of accommodation. One must also consider the unit costs of professionals within Social Services, whose services contribute to the total cost. Netten et al calculated unit costs for Social Workers, assistants and home carers:

<table>
<thead>
<tr>
<th>Professional</th>
<th>client related work – cost/hr</th>
<th>face to face work- cost/hr</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Worker</td>
<td>£23</td>
<td>£86</td>
</tr>
<tr>
<td>Social work assistant</td>
<td>£15</td>
<td>£46</td>
</tr>
<tr>
<td>Home carer</td>
<td>-</td>
<td>£9.39</td>
</tr>
</tbody>
</table>

One could therefore hypothesise a case of a more able person with autism who lives independently, and whose needs are met by social work support and three home care visits a day. Based on twice-monthly visits from a Social Worker, the service cost would be: £3,819 a year.

Jarbrink and Knapp use a combination of the above sources, and estimate that for people with accompanying learning disability and autism the annual cost would be £29,378, and for people with high functioning autism it would be £4,302.

However, the Audit Commission found that there were wide variations in charging systems across local authorities - in one local authority someone may pay £110 for home care services whilst the same service would be free in another. The report found that “most disabled users often face the highest charges, with some councils’ charging policies taking no account of other costs of disability or else taking a high proportion of user’s disability-related benefits”.

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49 Netten A, Dennett, J, Knight, J. (1999) Unit Costs of Health and Social Care, PSSRU, Canterbury
51 Audit Commission, (May 2000), Charging with Care – How Councils charge for Home care, London
IMPACT ON SOCIAL SERVICES - RECOMMENDATIONS

• The 1999 Health Act encourages partnership working, as do the gradual development of Primary Care Trusts around the country, and the proposed new Care Trusts. There is a need for a complete commitment to pooled budgets, to prevent unnecessary bureaucratic delay. A suggested model, (based on the principle behind the NHS and Community Care Act), is the specialist area team. This would hold a pooled devolved budget from health, education and social services. The team would organise care packages from a range of local services, including NHS, Social Services, LEA, voluntary and the private sector.52

• The planned post qualifying training strategy for Social Workers, to be overseen by the General Social Care Council,53 should include autism awareness training for mental health and learning disability teams.

• The inequality in home care and day centre charging nationally needs to be addressed, taking into account the evidence presented earlier that informal carers are already considerably subsidising community care. A recent Mencap report on charging for day centres recommends:
  i. the abolition of charging for non-residential community care services particularly day centres.
  ii. government-issued guidelines directing local authorities not to impose charges on adults that will need to be paid out of Income Support
  iii. local authorities should not take disability benefits into account when charging people with a learning disability for non-residential services, particularly day centres.
  iv. the government should issue guidance to local authorities on charging for non-residential care services, including a clear definition of what amount is a reasonable charge and how disability-related and basic costs should be treated.
  v. the government should issue guidance to local authorities on introducing and reviewing charging policies. Clear guidance on what information should be provided to a service user and their appeal rights should also be included.54

• The use of direct payments should be promoted and encouraged

54 Mencap Campaigns Department (Feb 1999) Fully Charged, Mencap, London
4. IMPACT ON THE HEALTH SERVICE

4.1 Difficulties with diagnosis

There is no simple blood test or brain scan that can detect autism. Diagnosis is therefore based on a complex interpretation of a child's observed and reported behaviours, following internationally agreed criteria. This is subject to personal interpretation by the professional, and is therefore not a consistently sharp tool. Furthermore, children with autism often have accompanying learning difficulties. It may be hard to separate the effects of autism from the other learning difficulties, and this requires a skilled clinician.

In practice, there is often a significant time lapse between parents first suspecting that their child has difficulties, and actually receiving a diagnosis. Baron Cohen has identified four reasons why there is often a delay in diagnosis.

1. The access point for diagnosis will be the general practitioner, who will not be trained in detecting autism at a young age.
2. There is nothing in current developmental tests which would alert a health professional - tests are generally for motor, intellectual and perceptual development. All of these may appear normal in autism.
3. GPs may not be familiar with autism, and may not spot signs which would be obvious to an expert.
4. Current medical criteria for autism emphasise difficulties in social development and communication development, both of which are difficult to assess in pre-school age children.

It may also be that professionals are unwilling to give what they see as a label to families, or they feel a need to conceal a diagnosis. This denies families the opportunity to find autism specific services or techniques to suit the very particular development pattern of people with autism, in a misguided attempt to protect them. Diagnosis has been described as a signpost, not a label.

"I was fed up with professionals pussy-footing around, afraid to say the dreadful word 'autism'. It seems that the very word 'autistic' is taboo."

Similarly, since the Warnock Report, the education system in particular has tended to shy away from diagnosis, as it has been seen as ‘labelling’ or ‘stigmatising’. However, educationalists specializing in autism would argue that it requires a very specific approach to learning, and so a clear diagnosis is vital for ensuring the right educational provision.

Diagnosis of an autism spectrum disorder at a young age is important for families, not only to have clear information about their child's autism or Asperger syndrome, but also to allow for the earliest intervention for the child. It is generally agreed amongst professionals that early...
intervention is critical to give the child the best hope of reaching their full potential. Research is underway into the cost-effectiveness of the earliest intervention, with many practitioners of the opinion that savings could be made. For example, early intervention can help to minimise or avoid difficult behaviour which could make the difference between mainstream or special schooling, or supported living or residential care in adulthood. In practice, however, according to voluntary organisations such as the NAS and PACE, rapid diagnosis, and a seamless transition to support and intervention rarely happens – the NAS report ‘opening the Door’ found that: “43% of respondents were not given any advice about where to go for help/support/counselling or further explanation” and 49% rated the help they were given as ‘very poor’.  

In short, and as one parent expressed the experience of many: “The whole process is far too slow and seems to depend on the parents' persistence in pushing for a diagnosis. Months seem to go by waiting for appointment after appointment. This really prolongs the agony of what is inevitably, in any case, a painful process”.  

Diagnostic protocols are being developed by the National Initiative in Autism, Screening and Assessment (NIASA).  

4.2 Cost of Health Care  

People with autism may need a selection of specialist health care professionals. These might include (the following are estimated unit costs):  

- A consultation with a Clinical Psychologist around for example, anxiety, obsessional behaviours, or sleep disorders would cost of £59 per hour.
- Similarly, a community Speech and Language therapist who an average child in school would ideally see every 2-3 weeks, costs c.£35 per hour of client contact, or c.£37 per hour of home visiting.
- People with autism or Asperger syndrome are commonly offered support by community Occupational Therapists at £196 per care episode. Occupational therapists are involved to tackle various issues, ranging from difficulties in holding a pencil, to the ability to get dressed, wash, and prepare a meal.
- Community physiotherapists may be involved in care of people with Asperger syndrome who commonly have motor problems or dyspraxia. An appointment cost of £197.

Other professionals may include health visitors, input from a child clinical psychiatry team, or child clinical psychology team, as well as input from an educational psychology team member, district nurses, community psychiatric nurses, dieticians, GPs, paediatricians, gastroenterologists and consultant psychiatrists.

Costs per individual over a lifetime are impossible to calculate, as there are too many variable situations, but would clearly be quite considerable.

63 NIASA comprises of representatives from all those professional groups involved with the early detection and treatment of autism – paediatricians, child psychiatrists, speech and language therapists, psychologists and health visitors
64 Netten, A., Dennett, J, Knight, J, (1999) Unit Costs of Health and Social Care, PSSRU, Canterbury
4.3 Mental Health

4.3.1
Research has found clinical depression to occur in 40% of adults with Asperger syndrome, with comorbidity of depression and other psychiatric disorders was found in 65% of the sample.65 Despite the small sample in this study, and the fact that it was composed of people who presented to a psychiatric unit, the findings are borne out in a recently published NAS survey report. This found that across the spectrum, one third of people had experienced mental health problems, including anxiety, depression and suicidal episodes. These figures rose to 45% of those diagnosed in their 20s, and 50% of those diagnosed after the age of 30.66

Jarbrink and Knapp made a calculation based on the assumption that the use of inpatient psychiatric services is at least four times higher for people with high functioning autism than for the general population: “With the assumption of no increased use of other hospital services due to the disorder, this resulted in an average annual cost of £480 from the age of 10 and throughout life”.67

However, despite the cost implications of the under-identification of mental health problems, isolation and depression can be prevented by relatively low cost support services.

For example, a London-based Asperger Syndrome social group organises regular meetings and trips - a simple low cost scheme which is of great benefit to the members that requires low level facilitation. Some Local Authorities also offer Social skills training that aims to teach some of the rules of social etiquette which are learnt naturally by most people, but which people with Asperger Syndrome need additional help to learn. This would include the avoidance of behaviours that others find anti-social such as inappropriate conversation, rituals, hyperactivity, and odd physical movements.

Thus social support programmes are believed to actively prevent a mental health breakdown following social exclusion in many cases. Currently, according to the NAS survey of members, 28% of people with autism or Asperger syndrome have access to social groups, and only 44% had received any social skills training.68

- Powell's study of people with Asperger syndrome in Avon69 recommends that Community Mental Health Teams in particular need an increased awareness of Asperger syndrome. Brogan discovered in her study of professionals' autism awareness that after only a one hour training course all the attendants showed an increased number of correct responses on an autism questionnaire - on average 85 percent of responses were correct after the session, compared to 66 percent before the session.70

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4.3.2
There are two contrasting problems with diagnosis of mental health problems for people with autism or Asperger Syndrome. The first is that additional mental health problems may not be picked up, and the second is that the problem may be misdiagnosed.

Firstly then, many people with autism or Asperger syndrome may not have their mental health problems identified as they may be perceived to be a manifestation of their autism. Ghaziuddin et al suggest that many people with autism and Asperger syndrome may have undetected additional mental health problems - most commonly depression, but also other conditions such as ADHD (Attention Deficit Hyperactive Disorder). 71

Secondly, an additional and avoidable cost to the health service is the misdiagnosis of mental health problems in people with autism. People with autism or Asperger syndrome are commonly misdiagnosed as schizophrenic despite evidence in the research field that people with autism or Asperger syndrome are no more likely to have schizophrenia than amongst the general population.72

In particular, neuroleptic drugs are often incorrectly given to people with autism when autistic characteristics and/or expressions of anger or frustration are mistakenly treated as psychotic. These can have very unpleasant side effects, particularly for people with autism, and when they are perceived to be having little effect, the doses are often increased. There is increasing evidence that old-style neuroleptic drugs were, and continue to be prescribed inappropriately to people with autism or Asperger syndrome. Murray studied people with autism who had been incorrectly prescribed neuroleptics, and estimates that: "If one fifth of one third of the estimated 150,000 people with serious learning disabilities in the UK have costs equivalent to the average [in the study] then the annual NHS neuroleptic-related costs would be £6,600,000". 73 This concern is also reflected in the Learning Disability White Paper: “Studies of the management of people with challenging behaviour has shown an overdependence on the use of psychotropic drugs with poor outcomes as a consequence”. 74 Often, anxiety and challenging behaviour relating to stress can be treated by alternative (and cheaper) methods, such as changes in environment, staff training or clear structure.

There are however newer ‘atypical’ neuroleptics, and some initial studies suggest that, for instance, Risperidone has fewer adverse side effects, and has been found to assist with behaviour such as stereotypies or aggression. 75 Some cautious use of medication has been demonstrated to be extremely effective, and so there is an urgent need for further research which is autism specific, as people with autism sometimes have unusual adverse effects to medication. Gringras and McNicholas have devised a detailed protocol for use when prescribing psychotropic medication for children, which covers aspects such as side effects, informed consent and school liaison. 76

74 Valuing People – A New Strategy for Learning Disability for the 21st Century, March 2001 p60 Department of Health
75 Riddle, M, Kastelic, E and Frosch, E 'Paediatric Psychopharmacology' Journal of Child Psychology and Psychiatry Vol 42 no1 pp73-90 (2001)
4.4 Detecting the Causes of autism - the cost of research

There is a growing body of biochemical and immunological research that maintains that autism may have a physical cause other than that traditionally hypothesized (brain damage either before or shortly after birth, or a sole genetic cause).

Some theories propose that simple interventions can dramatically improve functioning in some people with autism. Dr. Andrew Wakefield et al have recorded dramatic improvements for example, on treating children for gastro-enteritic problems.\textsuperscript{77} Shattock\textsuperscript{78} and Reichelt\textsuperscript{79} have discovered that there are increased levels of peptides from both gluten and casein in the urine of people with autism, indicating a ‘leaky’ gut. These substances are crossing the gut wall and entering the bloodstream, and possibly affecting brain development. Similarly, Waring et al have recorded dramatic results by treating children with autism with Epsom Salts to account for their deficits in Sulphates.\textsuperscript{80} Anecdotally, many parents and care professionals report great improvements in behaviour due to simple dietary changes.\textsuperscript{81}

All this research is very much in its early stages, and has been conducted on with low resources. However, if the findings are correct, the cost benefits of treatment are clear, as behavioural problems are reduced and learning abilities increased. There is a need for much more research to either confirm or refute these claims.

IMPACT ON THE HEALTH SERVICE - RECOMMENDATIONS

• There is a need for early diagnosis nationwide. The Government should ensure that the findings of NIASA are given national application, in collaboration with the Departments of Health and Education.

• The Royal Colleges should address the need for increased awareness, by introducing a national strategy of training for all general practitioners, health visitors, and mental health professionals in detecting autism, and in identifying Asperger Syndrome as opposed to mental health problems.

• Review of the use of neuroleptics in the treatment of people with autism or Asperger syndrome. Murray makes several recommendations for action with a view to avoiding the prescription of older style neuroleptics for general psychosis. These include
  • Prescribing support software should include an autism awareness package;
  • Relevant information to be included in the "The National electronic library for Health" for doctors, patients, and carers;
  • Training for members of the care network in identifying and monitoring drug side-effects;

\textsuperscript{78} eg Shattock, P, Kennedy,A, Rowell, F and Berney, T ‘Role of Neuropeptides in Autism and their relationship with classical neurotransmitters’ Brain Dysfunction Vol 3 pp328-345 1990
\textsuperscript{79} eg Riechelt, K et al ‘Biologically active peptide-containing fractions in schizophrenia and childhood autism’ Adv. Biochem. Psychopharmacol. Vol 28 pp 627-643
\textsuperscript{81} eg Allergy Induced Autism http://www.autismmedical.com/
- Increased acknowledgment by mental health practitioners of carers’ observations;
- stronger advocacy networks.

- In addition, protocols for administering medication for people with autism should be universally applied.

- More Research
  The Department of Health has recently commissioned the MRC to investigate the state of current research on the incidence, prevalence and causes of autism, and identify future possible research areas for future development, with findings due in Autumn 2001.\textsuperscript{82} The recommendations should be taken forward as soon as possible. Similarly, there is a mapping project underway based at the Institute of Child Health looking at Autism research in general. Findings from this should identify further gaps in research, which need to be addressed.

\textsuperscript{82} DoH Press Release 5 March 2001
5. ELIGIBILITY CRITERIA AND THE COST OF ‘FALLING THROUGH THE GAPS’

5.1 The Unseen Population

Many adults with autism and Asperger Syndrome commonly fall through the gaps in the services and do not receive any support from Social Services or Health Services. Two local studies, one in the Avon area, and one in Glasgow, have highlighted these gaps.83

The Avon study found that according to prevalence estimates there should be 2800 adults with Asperger syndrome living in that area. However only 120 adults were receiving a service. In other words, services are in contact with only 5% of people who may be entitled to an assessment of their needs under the NHS and Community Care Act. Whilst some of these people may not require a service, others may not be aware that they can receive a diagnosis, and others have approached health or social services and been refused help. The Glasgow report cites a similarly low rate of provision compared with estimated prevalence.

The Glasgow report confirms anecdotal evidence that the structure of many local authority Social Services is such that they do not accommodate people with Asperger syndrome - the Mental Health Team criteria exclude them, as do the Learning Disability Team criteria. Typically people will only be fitted into a service if they have additional severe and enduring mental health problems. People with Asperger syndrome may have very a high IQ, but still be disabled as a result of their lack of social awareness, and will therefore need support.

These findings have since been borne out in the National Autistic Society survey report Ignored or Ineligible? The reality for adults with autism spectrum disorders which found that only 38% of adults with autism and Asperger syndrome had a community care assessment (CCA). Of those who had an CCA, the majority had no lead agency (66%), and had to fight for resources between agencies, and different teams. Furthermore, of those who had a CCA, only 45% are actually receiving the services specified in the assessment.

People with autism who are more able often fit neither in learning disability teams nor mental health teams, and struggle on without any professional support, only receiving a service when they are suffering a crisis, such as a mental health crisis.84 Preventative health and social care, prompted by an increased awareness, would be more cost efficient than crisis intervention.

It could be argued therefore that there is a huge cost saving at present because those who are vulnerable are either not being identified or not getting a service because they do not fit neatly into bureaucratic structure. However, the cost of subsequent mental health breakdown requiring treatment, due to the lack of support and isolation, is not known.

84 33% of adults had mental health problems according to the NAS report Ignored or Ineligible? The reality for adults with autism spectrum disorders (NAS 2001).
5.2 Mental Health and Criminal Justice
The link between autism spectrum disorder and crime should not be over emphasised. It is widely believed that offending rates are in fact low, if not lower than for the general population due to the particular affection for rules which most people with autism or Asperger syndrome display. However, Howlin states: "On the whole rates of offending in this group are probably very low, but because of the nature of the deficit, if criminal acts are committed, it can be very difficult to provide the offender with the care or understanding that is necessary to avoid future offences". 

A study of Special Hospitals found a number of people with Asperger syndrome and high functioning autism in Special Hospital settings. Though there was no over-representation, several of this group had been misdiagnosed with conditions such as Schizophrenia. The report found that people with Asperger syndrome were found to remain in special hospitals longer than others who had committed similar crimes. The report also held that in many cases diagnosis could actually have prevented admission. This finding therefore, has both human rights and cost implications, as the high staffing and security regime of a special hospital makes a bed there extremely expensive.

- Unnecessary costs may be occurring if people with autism or Asperger syndrome are passing through the criminal justice system undetected — at risk of a "revolving door syndrome". If their condition has not been diagnosed, people will not receive the appropriate therapy and environment they need, and are at risk of re-offending if they are simply returned to the community without thought to what triggered the crime. A Department of Health working group on people with learning disabilities or autism reviewed services for Mentally Disordered Offenders. The finance group recommended that: “planning decisions about services for mentally disordered offenders, at local and national level, should take account of the cost to all agencies which work with this group. This includes the future cost of deterioration in a person’s condition when effective early intervention is denied”.

- There has been no research into people with autism and Asperger syndrome in the prison population as yet.

5.3 Employment opportunities
There is very little employment support for people with autism. Although they may be highly qualified, people often have problems maintaining permanent employment due to their difficulties in interacting with people.

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"It is estimated that there are approximately 18,000 adults with autism in the UK who are of normal intellectual ability, but only around 20 - 25% are likely to be employed, and occupational status, even amongst those in jobs, is very low".\(^8\)

In fact, the NAS report 'Ignored and Ineligible' found only 6% of adults are in full time employment, with 4% in part-time employment.\(^9\)

Not only is this a frustrating waste of education and abilities for many people, it has a wider social impact: "Failure to transfer the skills acquired through education to the workplace is a clear waste of resources. Continuing an unnecessary reliance on state benefits is also extremely expensive, as are the costs of treating psychiatric disorders relating to long-term unemployment".\(^10\)

Howlin and Peacock found that most supported employment schemes which are in place to address this problem tend to concentrate on low level unskilled jobs, which are not suitable for the complex needs of people with Asperger Syndrome who may have very good qualifications.\(^11\)

The National Autistic Society has begun to bridge this gap with a scheme called 'Prospects', which gives people support in applying for jobs, trains employers and provides on the job training. There are Prospects offices in London and Glasgow to date, and an outreach worker in Sheffield, which leaves a large part of the country without autism specific employment support. A study of the London project found encouraging results - the jobs found through the scheme were generally far better matched to people's abilities, with one individual actually earning more than his employment support worker.\(^12\)

A study on the cost effectiveness of supporting people with severe learning disabilities in employment as opposed to in a day centre made the following recommendation: "Further service development is required if people with intellectual disabilities and particularly those with more severe disabilities are to be given greater opportunities to engage in occupations which are typically pursued by people without disabilities. The contribution of employment in this endeavour cannot be overlooked and, therefore, exploring how supported employment can be implemented successfully with people with high support needs is an important priority".\(^13\)

**Cost Benefit**

Whilst a full cost benefit study on Prospects is planned, early findings are encouraging.

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\(^10\)Mawhood, L and Howlin, P 'The Outcome of a Supported Employment Scheme for high-functioning adults with autism or Asperger Syndrome' *Autism* 1999 Vol 3 (3) p229-234


\(^12\)Mawhood, L and Howlin, P 'The Outcome of a Supported Employment Scheme for high-functioning adults with autism or Asperger Syndrome' *Autism* 1999 Vol 3 (3) p229-234, Sage and NAS, London

The initial outlay of employment support is very expensive, but the amount of support needed is reduced over time. There is also a reduction in benefits claimed. The average monthly amount received in benefits prior to the scheme was £241.87 per person. At the end of the two year study it was £78.57. The overall monthly reduction was £163.30. Any cost benefit will be difficult to predict exactly, as the preventative costs of, for instance, someone unoccupied developing chronic depression, and the accompanying cost to the Health Service, are hard to estimate.

There are also people who have autism and accompanying learning disabilities, who could be employed with support, but are excluded by bureaucracy. For many the 'benefits trap' is such that they cannot work for more than fifteen hours a week without losing all their vital benefits, so they are denied the opportunity to offer back, and to feel the sense of worth which employment can bring.

**IMPACT OF ADULTS FALLING THROUGH THE GAPS - RECOMMENDATIONS**

- **Health and Social Services** The 1999 Health Act set out a framework for more joint working and pooled budgets - this should be utilised to create a niche for people with autism, particularly those with at the higher end of the spectrum. Social Services Community Care Plans should identify a lead service and named manager for adults with autistic spectrum disorders. The government should issue multi agency guidance with regard to autism, on the use of the framework in the 1999 Health Act.

- **Crime**
  i. Services for people with autistic spectrum disorders in the criminal justice system should be supported by early intervention systems, which would be ultimately cost effective.
  
  ii. The Home Office should commission a survey of the prison population: although we have evidence of people with autism and Asperger Syndrome in Special Hospitals, there are no figures for people in prisons.

  iii. The effective early intervention recommended by the Department of Health report can only be achieved if there is greater awareness in the Criminal Justice system, throughout police, probation and court systems.

- **Employment opportunities** should be extended, both for those who can work in the open market with minimum support, and those with higher needs who can nevertheless contribute, given adequate assistance. This relies on employment advisors having appropriate training to recognize autism and Asperger syndrome, which can be a hidden disability

**OVERALL CONCLUSION**

A summary of all the recommendations of the report are in the executive summary at the beginning. To conclude, whilst there is the need for more financial outlay for people with autism, it has been demonstrated that preventative work to avoid crises for individual with autism and their families can save money in the long term, and enable people with autism to achieve their full potential.