

# Taking Responsibility

Good practice guidelines for services  
– adults with Asperger syndrome



Andrew Powell  
The National Autistic Society

Grant funded by the Department of Health

# Taking Responsibility

Good practice guidelines for services  
– adults with Asperger syndrome



**Andrew Powell**  
**The National Autistic Society**

## Acknowledgements

These guidelines are the result of the Avon Asperger Syndrome Project 1999-2002, funded by the Department of Health. With thanks to Elaine Cooper and colleagues at Wellington House.

Thanks to National Autistic Society colleagues Judith Barnard, Anne Cooper, Eileen Hopkins, Angie Lee-Foster, Richard Mills, Terry Mooney, Julie Moynihan, Rachel Pike, David Potter and Jan Snook; Fiona Loynes (All Party Parliamentary Group on Autism); Andrea MacLeod (West Midlands Autistic Society) and many others who commented and advised on aspects of the guidelines.

Dedicated to the parents of the Avon Branch of the National Autistic Society, the members of the Avon and Somerset Asperger Pub Group and Dr Peter Carpenter.

# Contents

|  |    |
|--|----|
| Executive summary  | 3  |
| Introduction   | 7  |
| Key principles   | 9  |
| Senior manager responsibility  | 13 |
| Planning Group   | 14 |
| Asperger syndrome audit  | 16 |
| Service needs  | 17 |
| Register of people with autistic spectrum disorders  | 18 |
| Training strategy  | 19 |
| Support pathway for community care assessment  | 23 |
| Service provision  | 28 |
| Practical support services   | 31 |
| Relationship support services  | 33 |
| Health services  | 40 |
| Support pathway for diagnostic assessment  | 42 |
| Information for people with Asperger syndrome and their families                                 | 45 |
| Crisis intervention  | 46 |
| Secondary schools – preparation for adult life   | 47 |
| Transition planning  | 49 |
| College or university  | 54 |
| Post-diagnostic support  | 56 |
| Carers’ needs  | 59 |
| Employment support services  | 61 |
| Benefits   | 63 |
| Accommodation services   | 64 |
| Partners and families  | 69 |
| Criminal justice   | 70 |
| Conclusion   | 71 |
| Appendix A – UK Asperger syndrome/autistic spectrum disorder<br>research and local audit reports | 73 |
| Appendix B – Asperger syndrome organisations   | 75 |
| Bibliography   | 78 |



## Executive Summary

Asperger syndrome is a condition on the autistic spectrum (Wing, 1996). It is the term most commonly used to describe people with autism who have average or above average IQ (American Psychiatric Association – DSM-IV; World Health Organisation – ICD-10).

There are varying estimates of prevalence of Asperger syndrome. One study suggests prevalence is approximately 1 in 300 people (Ehlers and Gillberg, 1993). It affects more males than females.

These guidelines are for use by services that have a responsibility to meet the needs of adults with Asperger syndrome. This includes social care, health, housing, secondary schools, colleges, universities, Connexions, employment and other agencies. The guidelines are necessary because whilst the term Asperger syndrome has become slightly more familiar amongst professionals and the general public, there is little evidence, as yet, of any improvement to the lives of adults with Asperger syndrome.

It is time for services to translate the increased awareness into tangible effect. Evidence of 'what works' is now emerging, and these guidelines give direction for supporting people with Asperger syndrome into better futures.

Some people with Asperger syndrome will not require any statutory services. However, the majority of adults need understanding and support from the wide range of agencies they come into contact with.

There is a need in some cases for specialist services but there is a wider need for existing services to develop specialist approaches.

- Across the UK adults with Asperger syndrome continue to be explicitly excluded from accessing statutory health and social care because they do not 'fit' the perceived remit of learning disability or mental health services.
- 65% of adults with Asperger syndrome have not received a community care assessment. (Barnard et al, 2001).
- Adults are also often excluded from supportive college/university education, housing and employment opportunities due to lack of understanding and resources.

These guidelines are presented as a way forward, to put an end to the ongoing confusion about what is needed and who is taking responsibility.

***'I don't want another generation of people with autism to go through the hell I've been through.'***

**(Person with Asperger syndrome)**

***Only 3% of adults with Asperger syndrome are living fully independent lives.***

**(Barnard et al, 2001)**

# The four major recommendations

## 1. Senior manager with responsibility for adults with Asperger syndrome

Each local authority should ensure that a senior manager is given overall responsibility for services for people with Asperger syndrome. The senior manager could be from either health or social services, with good understanding of and links to both. He or she should have received appropriate training and have an interest in Asperger syndrome. He or she should also be closely involved with the main planning and commissioning fora.

At the present time in the UK, this basic recommendation has still not been implemented, despite consistent lobbying from The National Autistic Society (NAS), autism societies, people with Asperger syndrome, families and practitioners.

*Commitment to Asperger syndrome must come from director/chief executive level downwards.*

Unless a senior manager is given responsibility to develop and plan provision, services will continue to be woefully inadequate or unnecessarily expensive.

## 2. Multi-disciplinary Planning Group

The senior manager should establish a multi-disciplinary Planning Group for adults with Asperger syndrome. The Planning Group should have representation from all relevant disciplines including health, social care, housing, secondary schools, Employment Service, Connexions, colleges, local universities, independent sector providers and voluntary groups.

People with Asperger syndrome and their families should have their views represented directly to the Planning Group.

Asperger syndrome is a complex condition and meeting the needs of adults requires a multi-disciplinary approach. People will vary in their needs for support, but unless all relevant agencies are aware of each other's role and pull in the same direction, the outcomes for individuals will be jeopardised. The interdependence of services is often crucial. For example, one person may be able to cope at college, so long as her housing support needs are met. Another person can hold down a job, but only if he receives visits from his community psychiatric nurse.

The establishment of a Planning Group will allow multi-disciplinary links and understanding to develop. It also provides a basis for joint initiatives, training and commissioning.

## 3. Decision about which team(s) will provide assessment of need under the *The NHS and Community Care Act 1990*

This decision is the first key to service provision. The manager should consult with health and social care colleagues and then establish clear protocol for community care assessment of need.

These guidelines will be less effective unless local authority decision makers make a decision about who is taking responsibility for community care of adults with Asperger syndrome.

This long neglected issue within most local authorities in the UK has a profound impact on the lives of people with Asperger syndrome and their families. People with Asperger syndrome, their

families and the social and health care practitioners trying to support them, are being let down by a lack of decision making within local authorities and health trusts.

Local authorities should be providing a 'level playing field' for adults with Asperger syndrome. Families of those affected by Asperger syndrome do not expect special treatment because of the diagnosis. They are not asking for better services than other people, or to be allowed to 'jump the queue' for assessment or by-pass eligibility criteria.

What people with Asperger syndrome and their families do expect is fair and equal access to assessment, which is their legal right under *The NHS and Community Care Act 1990*.

#### 4. Service provision

There is now enough information about the sorts of services that people with Asperger syndrome, their families and practitioners require, to make service development a priority.

Seventeen local authority and health trust research audits, National Autistic Society reports and other projects have consistently reported the same list of needs amongst adults with Asperger syndrome.

It is time for health and social services, housing, schools, colleges, universities, employment agencies and Connexions to take positive action and implement these recommendations.

### Service needs of adults with Asperger syndrome – findings of 17 UK autistic spectrum disorder national and local research/audit reports (1995-2002)<sup>1</sup>

1. A training and awareness programme to increase professional understanding across a wide range of community services including social, housing, school, continued education, health, employment and Connexions services.
2. A clear support pathway so families know whom they can contact to request assessment regarding possible diagnosis.
3. A clear support pathway so families know whom they can contact to request assessment under *The NHS and Community Care Act 1990*.
4. An improvement in employment opportunities and support.
5. Interventions to reduce social isolation.
6. Interventions to reduce clinical mental health difficulties.
7. Interventions to develop independent living skills and relationships.
8. Better post-diagnosis emotional support, information and advice for people with Asperger syndrome.
9. A range of appropriate supported housing options.
10. Better social and academic support and learning opportunities within secondary schools during transition and in continued education.

## ...continued <sup>1</sup>

11. Carers' needs to be assessed and met, including education/information, advice, counselling (including genetic counselling) and 'respite' type services, such as befriending for their sons and daughters.
12. More appropriate service provision. Many adults are placed in services that are not suitable for Asperger syndrome, due to poor provision or misdiagnosis.
13. Access to advocacy services, for families and people with Asperger syndrome.
14. Sensitive crisis services (not necessarily mental health in-patient).
15. Forensic services (to support the few people who display behaviour likely to put themselves or others at risk of harm).

Without appropriate provision many adults with Asperger syndrome will become socially isolated, drop out of school or college, be unable to work, suffer mental health problems and psychological breakdown (Howlin, 1997). Wolff and McGuire (1995) also highlight the suicide risk for people with this condition.

Lack of support services for people who are experiencing difficulties can lead to police involvement, prison sentences, admission to psychiatric units and trial-and-error drug treatments (Shah, 1999).

For many, these consequences could be avoided or greatly reduced by a relatively low level of ongoing support, saving severe distress and the costs of inappropriate agencies becoming involved.

The time to provide appropriate support and understanding is well overdue. The National Autistic Society continues to offer its expertise and experience to any local service that takes the opportunity to develop and improve provision for people with Asperger syndrome.

<sup>1</sup>Includes national National Autistic Society reports (Barnard et al, 2001; Barnard et al, 2000; Stirling and Prior, 1999).

# Introduction

These guidelines are designed for local services planning to meet the needs of adults with Asperger syndrome. It is the result of a three year project (1999-2002) funded by the Department of Health to research the service needs of adults with Asperger syndrome.

Asperger syndrome is an autistic spectrum disorder (Wing, 1996). It is the term most commonly used to describe people with autism who do not have a learning difficulty (American Psychiatric Association – DSM-IV; World Health Organisation – ICD-10).

There are varying estimates of prevalence of Asperger syndrome. More recent childhood studies suggest prevalence is approximately 1 in 300 people (Ehlers and Gillberg, 1993; Kadesjo et al, 1999; Baird et al, 2000)<sup>2</sup>.

These guidelines will be of use when planning services not just for those with a diagnosis of Asperger syndrome but also people who are termed ‘high functioning’ or ‘able’ autistic. They aim to give local authorities, health trusts and other services a strategic framework to their work, and to give ideas for service improvements.

Although the guidelines are concerned with services for people over 18, there are brief guidelines for secondary schools and during transition as education is closely related to positive outcome.

These guidelines cover local services such as social services, education, health, housing and nationally funded bodies such as the Employment Service and Connexions. They need to be implemented in close liaison with other stake-holders such as voluntary agencies and independent sector providers.

People with Asperger syndrome and their families should be at the centre of all planning.

## Why are guidelines required?

Lack of awareness and knowledge about Asperger syndrome often contributes to the use of services and interventions that exacerbate rather than minimise the difficulties.

Guidelines are necessary because Asperger syndrome is generally not recognised by local authorities and other public services as a condition requiring an assessment of need, and people with the diagnosis still find themselves ‘ignored or ineligible’ (Barnard et al, 2001).

The majority of adults with Asperger syndrome receive no assistance from outside agencies; they feel isolated, and singled out as people whose disability is deemed unworthy of assistance.

There is, therefore, an urgent need for the development of services that allow better opportunities for people with Asperger syndrome to contribute and become more fully part of their community.

Without support to cope with the demands of a society that fails to understand their needs or difficulties, people will continue to experience, ‘stress and anxiety and even psychiatric breakdown’ (Howlin, 2000, p.79).

***‘They were helpful in as much as they were honest, ie after 19 you are on your own as there are no legal requirements for services – we’re not going to provide any.’***

**(Parent, in Barnard et al, 1997)**

<sup>2</sup>Chakrabarti and Fombonne (2001) study of 4 -7 year olds gave prevalence of about 1 in 900.

Increasing research confirms what practitioners have been reporting: adults with Asperger syndrome are at significant risk of mental health difficulties (Howlin, 1997), particularly affective disorders (Wing, 1981), and appear to fit the high risk 'suicide prone' category (Wolff and McGuire, 1995; Portway, 2000).

Local authorities and health trusts must acknowledge Asperger syndrome and work closely together with other agencies to meet the needs of individuals with this complex condition. This support must start in schools and extend through to continued education, employment, housing, social and health care.

# Key principles

## A different view of the world

People with Asperger syndrome have a unique cognitive style (Frith, 1991; Happé, 1994; Baron-Cohen et al., 1985; Hobson, 1993). Consequently people with Asperger syndrome experience the world in a way that is different to those without the condition (Lawson 1995; Sinclair, 1993; Willey, 1993).

This qualitative difference requires services and individual professionals to make the 'essential imaginative leap into the Asperger world' (Wing, 1998) viewing reality through the 'Asperger lens' (Cumine, Leach and Stevenson, 1998).

Unless local authorities and other service providers understand that people with an autistic spectrum disorder have a different view of the world, efforts to meet needs are likely to be ineffective and even counter-productive.

## A significant impairment

Asperger syndrome usually describes those people with an autistic spectrum disorder who have average to high IQ<sup>3</sup> and often relatively good expressive language skills. Nonetheless, they are a group who have by definition, 'clinically significant impairments in social, occupational or other important areas of functioning' (DSM-IV, American Psychiatric Association, 1994).

Despite their 'clinically significant impairments' people with Asperger syndrome are sometimes dubbed 'able autistic' or described as having 'mild autism'.

Whilst these terms help to differentiate between people with and without a learning disability, they can also be very misleading. Though some develop sufficient compensatory abilities to get along in the world, for all people with an autistic spectrum disorder, life is a struggle.

Several authors with autistic spectrum disorders describe these compensatory abilities as going against the person's natural inclinations and developed in reaction to the confusion of the social world. These coping mechanisms may be called 'facades' (Williams, 1992), 'masquerading' (Carrington and Graham, 2001), or simply, 'pretending to be normal' (Willey, 1999).

As a result of trying to 'fit in' many adults experience significant levels of anxiety (Attwood, 1998) and often develop other mental health difficulties, most commonly depression (Howlin, 1997, Tantam, 1991).

## Legal duty to assess (NHS and Community Care Act 1990)

It is essential that people with Asperger syndrome approaching their local authority are offered assessment of need under *The NHS and Community Care Act 1990*, and that local authorities establish a clear route for families to access support.

A diagnosis of Asperger syndrome does not mean that someone will meet eligibility criteria for local authority services. However, an assessment of need will nearly always be required to establish whether the individual's particular difficulties meet eligibility for services.

***'It does not matter how kind or helpful or well intentioned you are, unless you understand Asperger syndrome you will probably end up doing more harm than good.'***

**(Parent from Supporting Asperger Families in Essex)**

***'A significant problem seems to be that while both physical and mental disabilities are recognised, social disability is not!'***

**(Parent, Avon Branch)**

<sup>3</sup>There are a few people diagnosed with Asperger syndrome who have mild learning difficulties but generally the diagnosis tends to be used to describe those without intellectual impairment (ICD-10, DSM-IV).

## What Valuing People says about Asperger syndrome

The government does not consider Asperger syndrome a learning disability in the traditional sense, because people with the disability usually have average and above IQ scores:

*'This definition (of learning disability) covers adults with autism ...but not those who may be of average or even above average intelligence, such as people with Asperger syndrome.'*

*(Valuing People: A New Strategy for Learning Disability for the 21st Century, Department of Health, 2001)*

However, implementation guidance on the White Paper *Valuing People* explains that services may be offered to people with Asperger syndrome to meet their needs:

*'Adults with Asperger's Syndrome or higher functioning autism are not precluded from using learning disability services, and may, where appropriate, require an*

*assessment of their social functioning and social skills in order to establish their level of need.'*

*(Implementing Valuing People: A New Strategy for Learning Disability for the 21st Century, Department of Health, 2001)*

This government guidance should be used positively by local authorities and health trusts to provide adequate services for people with Asperger syndrome. There is already some excellent work being done by staff in learning disability services and this should be continued to enable people to develop independence.

However, despite the Department of Health guidance, current national practice is for people with Asperger syndrome to be sent between mental health and learning disability services, neither of which accepts responsibility for assessment, or provides services.

The NHS and Community Care Act 1990 does not specify which groups of people services may be provided for, as it recognises that people may be vulnerable for a wide variety of reasons and that it is a person's needs that require support not their IQ score or name of their disability.

Therefore whether Asperger syndrome is considered a learning difficulty, learning disability, mental health problem, developmental disorder, or anything else is not strictly speaking relevant to being able to access a community care assessment.

The NHS and Community Care Act 1990 section 47:

*'(there is a duty to assess) where it appears to a local authority that any person for whom they may provide or arrange for the provision of community care services may be in need of any such services, the authority shall*

*(a) carry out an assessment of his needs for those services; and*

*(b) having regard to the results of that assessment, shall then decide whether his needs call for the provision by them of any such services' (s.47(1)(a)).*

It is the legal duty of local authorities to look at the individual in need, rather than applying service user definitions to decide who gets an assessment.

### Individual differences

Whilst the 'triad of impairments' (Wing, 1981) is considered to be the common factor amongst all those with the diagnosis, it is important to remember that people with Asperger syndrome are individuals and everyone affected is different. People vary in personality, life experience, intellectual ability and genetic inheritance, which makes it crucial that strategies are not developed on the basis of limited understanding. Services need firstly to understand Asperger syndrome, but then also to tailor responses to individual need.

**'If someone with a head injury asked for services would he be told "sorry we cannot help, because you don't have a learning disability or mental health problem"?'**

**(Parent, Avon Branch)**

## Choices

The concept of choice can be a difficult one for people with Asperger syndrome. People will be able to make choices, but some may need to experience them first, before they can make a reasoned choice. Others will require considerable support to express their choices. This appears to relate to their particular thinking style – weak central coherence (Frith, 1994) that has a relative lack of flexibility, weaknesses in certain problem-solving skills, and difficulty imagining futures. It appears that ‘free choice’ can increase anxiety for many individuals with Asperger syndrome (Vermeulen, 2001).

Choice is one of the most important rights of the individual, and a thorough understanding of how the person with Asperger syndrome makes choices and what counts for ‘informed choice’ is crucial to good planning.

Even when someone with Asperger syndrome has made a reasoned choice, there must be a balance of choice against best interests (either of the individual or others). So rights have to be balanced against duty of care.

Very occasionally a highly structured, low choice, or even ‘restrictive’ environment is in the individual's best interests. This is clearly a contentious area, which requires careful risk assessment.

## Inclusion

Inclusion is an important philosophy embraced by many services, but it needs to be carefully examined when applied in practice, since ‘involuntary inclusion is as problematic as involuntary segregation’ (Sinclair, 1998, in Sainsbury, 2000 p.36). Inclusion is the philosophy and practice of including ‘marginalised’ people into the opportunities made available for everyone else.

So, the question for planners of adult services is: can this person with Asperger syndrome be successfully included into a service and have his needs met within an ‘inclusive’ environment?

Most services offered to adults with Asperger syndrome are services set up to meet the needs of adults with mental health or learning difficulties. Since Asperger syndrome is not itself a mental illness, nor is it a learning difficulty, many people with Asperger syndrome do not feel included at all.

The current practice of trying to ignore the differences in Asperger syndrome or fit people into inappropriate services does not promote a healthy sense of feeling included. Services need to develop greater knowledge of what Asperger syndrome is and find ways to include the person in a flexible way, appropriate to his or her needs, not just treating him or her the same as everyone else.

There also needs to be recognition that very occasionally people will require ‘involuntary inclusion’, in order to safeguard their mental/physical health. For example, in instances when people have lost their self care skills.

## The social model of disability and social identity

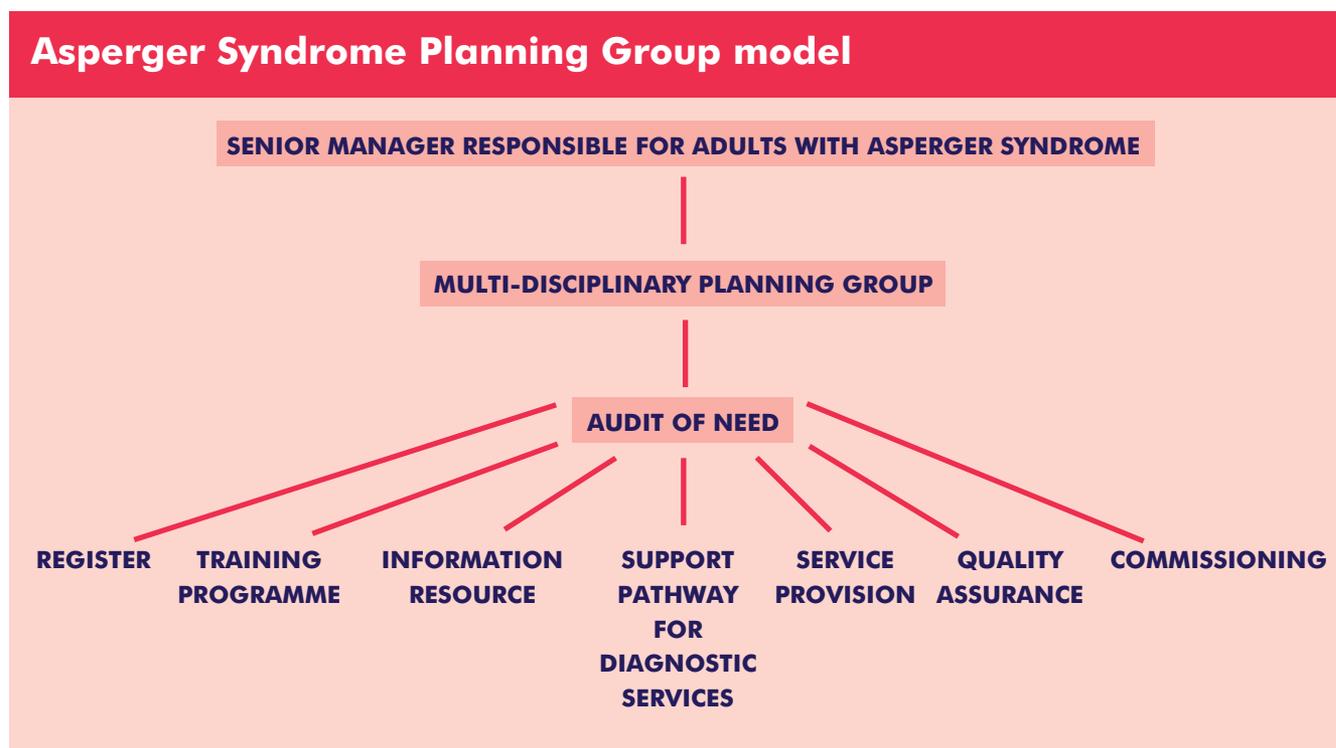
The social model of disability is very important to the planning and delivery of services. For too long people with a disability have faced a ‘medicalisation’ of their difficulties, which focuses the ‘problem’ within the individual, rather than the society which creates ‘disability’ by its attitudes and practices (Oliver, 1990).

Two things need to be said in reference to the social model. Firstly, it is important to look at the actual impairment in autistic spectrum disorders. Service provision that continues to ignore the specific needs of people with Asperger syndrome or tries to fit them into mental health or learning difficulties services, that are often inappropriate, represents poor practice.

Secondly, it is important to realise that people with Asperger syndrome have suffered for too long in isolation, being encouraged to believe that their impairment is their fault. People should be offered services that take account of their difficulties, build on their strengths and promote the emergence of a 'positive autistic identity' (Sainsbury, 2002).

Ignoring the specific impairment in autistic spectrum disorders and not accepting the individual's right to be different both serve to reinforce the notion that people on the autistic spectrum are not entitled to a separate social identity and that they are to blame for their own inability 'to fit in'.

# Senior manager responsibility



The central elements of the model are a senior manager responsible for adults with Asperger syndrome and the formation of a multi-disciplinary Planning Group.

The essential prerequisite of the model is for the senior manager to decide, after appropriate consultation, which team(s) will carry out the legal duty of community care assessment, for people with Asperger syndrome.

The senior manager responsible could be from either health or social services, and must have good understanding and links with both. The guidelines require health and social services to work together in their commitment to people with Asperger syndrome.

Preferably the senior manager should have commissioning powers. He or she should be involved with the main planning and commissioning fora such as Learning Disability Partnership Boards, Joint Investment Plans, Special Services Commissioning Groups and children’s services.

## Planning Group

Each local authority should establish a multi-disciplinary Planning Group on adults with Asperger syndrome. The Planning Group should have representation from senior staff within secondary education, health (including learning disability, mental health, psychiatry, psychology, primary care trusts, child and adolescent psychiatry), social services, housing, Connexions, further education, Employment Service, voluntary agencies, independent sector providers. The Group should also have represented the views of people with Asperger syndrome and carers, either directly on the Group or via a user forum.

The exact role of the Planning Group will vary according to awareness of Asperger syndrome and the degree of interest the local authority and health trusts have in developing appropriate provision. The Planning Group will link in with existing local planning and commissioning mechanisms.

### Tasks of the Planning Group

- **An Asperger syndrome audit** must be undertaken to establish prevalence, needs and services. This may be achieved by employing a project or development worker to identify numbers of people, types of need, service provision and training needs in the local authority. It may be a local support group member could undertake much of the work, under supervision.
- **A register** of people with an autistic spectrum disorder, including Asperger syndrome in the local authority/health trust area, should be maintained.
- **A training strategy** (for example using the NAS SPELL<sup>4</sup> framework to inform training approaches and content, or hosting 'good practice'/information days) should be implemented.
- **A support pathway for services** must be clarified. This will include an agreed multi-disciplinary protocol for how families and individuals access services; which team/s are responsible for community care assessment and how best to link with other services, for example education or employment. It must also cover working alongside people with additional physical/mental disabilities or addictions.
- **A support pathway for diagnostic assessment** establishing a common language and agreed paths to adult diagnosis must be developed.
- **An information resource** for people with Asperger syndrome and their families must be developed. This will contain information on accessing services, advice on aspects of adult life, welfare rights and local support groups.
- **Service provision** recommendations must be implemented (for example, establishing a social group for adults with Asperger syndrome via agreement with a local provider of mental health services; setting up a tertiary diagnostic service).
- **Quality assurance** should be established across service provision in the local authority and health trusts<sup>5</sup> and providers encouraged to do the same (for example, organising focus days on *Valuing People* principles; registering with Autism Accreditation<sup>6</sup>).

<sup>4</sup>SPELL is The National Autistic Society framework to services to people with an autistic spectrum disorder on an individual and organisational level. It stands for Structure, Positive approach, Empathy, Low arousal and Links.

<sup>5</sup>Each local authority or health trust should consider a departmental approach to good practice, and register with Autism Accreditation (for example – Oldham Learning Disability Services, North Yorkshire Social Services, Northgate and Prudhoe NHS Trust).

<sup>6</sup>Appendix B.

- **Commissioning** powers of the Planning Group will vary from area to area. Ideally the Planning Group may make decisions on commissioning new services, for example, setting up a new community support scheme to reduce out-of-area placements<sup>7</sup>. In another local authority, the Planning Group will feed into the main planning fora to influence commissioning, giving advice and information.

## Good practice – co-ordinated regional planning of service provision (Greater Manchester Consortium to develop local services for people with autism)

In 1997 directors of social services departments across the 10 Greater Manchester councils, working with The National Autistic Society Family Services Project worker saw the benefits of a collaborative, coherent approach to service development for people with autistic spectrum disorders. The first regional convention of the consortium was held in December 1998 and since then a further two conventions have been held.

Parents have been a major factor in the development of the project and continue to advise on service needs.

The councils are Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford and Wigan.

*One of the first tasks for each council was to collate statistics of people known to services, services already available and costs of out-of-area placements. This has shown how setting up local services will save costs and also demonstrates that savings can be shared across authorities.*

The 10 councils each contribute to the salary of a Family Services Project worker employed by the National Autistic Society. The Family Services Project worker helps the local Development Groups to improve their services.

For adults with Asperger syndrome in the Greater Manchester area there has been the development of social groups for young adults 16-25 (ASGMA)<sup>8</sup>, a specialist counselling service and a National Autistic Society befriending scheme amongst other initiatives.

In Oldham services for children with a disability have set up a project Mazoori – Bachche Aur Hum to reach ethnic minority groups by creating a video and other educational resources on three major disabilities, including autistic spectrum disorders.

*By meeting regularly councils can share good practice, resolve practice and process issues by collective regional strategy, share the services of a dedicated and cost-effective Family Services Project worker and set up co-ordinated regional services. Several councils share training initiatives and some services work across council boundaries.*

<sup>7</sup>One of the main reasons for setting up the South Staffordshire project was to research ways to reduce out-of-area placements. See Appendix A.

<sup>8</sup>Appendix B.

# Asperger syndrome audit

The services required by adults with Asperger syndrome are documented within these guidelines. Whilst implementation of these services should not be delayed, an audit of need will be useful to prioritise needs within the local authority and health trust.

1. It may be useful for a local authority or health trust to carry out its own audit by seconding a worker. At other times employing an outside agency may provide a more independent view.
2. Whoever carries out the audit must have knowledge of autistic spectrum disorders and may wish to consult previous audits for questionnaire formats.
3. The audit should be focused on likely areas of service need as identified in previous local Asperger syndrome research reports.
4. The audit should use a variety of methods to obtain information from families and people with Asperger syndrome. Many audits hold interviews after contact has been established via parents.
5. Questionnaires sent out to service providers should ascertain how many people are known to each service, the needs met by the service, training needs of staff and what services are required. Questions on quality assurance must be included, for example, how are users consulted and how is quality of life measured by and for users?
6. It may be necessary to obtain clearance from the local health authority ethics committee, depending on the types of data requested from families (for example, if identifying people for a register).
7. The results of the audit should be presented to the Planning Group to feed into the different functions of the group – developing a register, training strategy, support pathways, service development, and information resource.
8. Each Planning Group representative should examine the audit findings in order to formulate a training strategy and develop services, in collaboration with their respective service managers.

# Service needs

## Service needs of adults with Asperger syndrome – findings of 17 UK autistic spectrum disorder national and local research/audit reports (1995-2002)<sup>9</sup>

1. A training programme to increase professional awareness and understanding across a wide range of community services including social, housing, school, continued education, health, employment and Connexions services.
2. A clear support pathway so families know whom they can contact to request assessment regarding possible diagnosis.
3. A clear support pathway so families know whom they can contact to request assessment under *The NHS and Community Care Act 1990*.
4. An improvement in employment opportunities and support.
5. Preventative interventions to reduce social isolation.
6. Interventions to reduce clinical mental health difficulties.
7. Interventions to develop independent living skills and relationships.
8. Better post-diagnosis emotional support, information and advice for people with Asperger syndrome.
9. A range of appropriate supported housing options.
10. Better social and academic support and learning opportunities within secondary schools, during transition and in continued education.
11. Carers' needs to be assessed and met, including education/information, advice, counselling (including genetic counselling) and 'respite' type services, such as befriending for their sons and daughters.
12. More appropriate service provision. Many adults are placed in services that are not suitable for Asperger syndrome, due to poor provision or misdiagnosis.
13. Access to advocacy services for families and people with Asperger syndrome.
14. Sensitive crisis services (not necessarily mental health in-patient).
15. Forensic services (to support the few people who display behaviour likely to put themselves or others at risk of harm).

<sup>9</sup>Includes National Autistic Society reports (Barnard et al, 2001; Barnard et al, 2000; Stirling and Prior, 1999).

# Register of people with autistic spectrum disorders

**Using common estimates of prevalence<sup>10</sup>, within a local authority/health trust area with a population of 250,000, there are likely to be about 900 people who meet the diagnostic criteria for Asperger syndrome (approximately 200 children and 700 adults).**

Each local authority should have a 'classified register'<sup>11</sup> of people with autistic spectrum disorders in order to plan services.

However only 17% of health authorities have detailed data on autistic spectrum disorder incidence (Thrower, 2000) and 74% of social services departments have no record of people with autistic spectrum disorders (National Autistic Society, 1996).

It is clear local authorities and health trusts are only aware of a minority of people. What is unclear is how many of those 'not known' to services, would be eligible for community care and benefit from support from other services.

The number of people with Asperger syndrome requesting services is likely to increase over the next few years, as the diagnosis is more widely recognised (Barnard et al, 2002). Parents of children currently in full time education will expect adult services to be available and appropriate for their young adult sons and daughters.

1. A register of people of autistic spectrum disorders should be held by each local authority, as part of their disability register.
2. The register format should enable separate data analysis on Asperger syndrome, people with other autistic spectrum disorders and other disabilities.
3. Although best practice would be for local authorities to maintain information on autistic spectrum disorders using a common register, if a local authority does not have a current adult register then an autistic spectrum disorder specific register should be created in the interim.
4. There should be a shared system between health, education and social services.
5. Responsibility for the upkeep of any separate register should be clear.
6. It must be clearly explained to those who are asked if they wish to be on a register, what the register is to be used for, who has access to it and what benefits it confers.
7. Information from children's services about numbers of children with Asperger syndrome, should be passed on early to adult service commissioners and providers, so adequate plans can be completed. Changes in diagnosis should be noted.
8. Voluntary groups such as National Autistic Society Branches and other societies should be approached for information about people with an autistic spectrum disorder. With permission information may help to establish a register in areas where there is no local authority held data.<sup>12</sup>

<sup>10</sup>Ehlers and Gillberg, 1993; and Kadesjo et al, 1999; Baird et al, 2000.

<sup>11</sup>*Chronically Sick and Disabled Persons Act 1970* section 1(1), *National Assistance Act* section 29(4). Also a requirement for local authorities to hold a voluntary register for disabled under 18s – *Children Act 1989* paragraph 2 of Schedule 2.

<sup>12</sup>In Essex, for example, there are about 500 families with teenagers and adult sons or daughters with Asperger syndrome who are known to 'Supporting Asperger Families in Essex' (SAFE).

## Training strategy

Awareness of the term ‘Asperger syndrome’ has increased over the past 5 years. The continuing campaigning efforts of autism societies and groups in the UK, alongside media interest, have helped to raise the profile. However, a lack of real understanding amongst professionals (particularly in adult services) remains a cause for concern.

The complexity of Asperger syndrome requires that people who work alongside those with the condition are regularly and specifically trained to provide good quality care and support.

The Planning Group in each local authority should co-ordinate multi-disciplinary training programmes. The Group should also:

- look for joint funded training initiatives
- provide consultation to trainers
- maintain a directory of training providers, noting their specialisms
- encourage quality assurance/‘accreditation’ of training programmes – ie ensuring that training is consistent, of good quality, at the right level for participants and on a rolling programme
- ensure consistency with national training developments (for example, NVQ in autism, General Social Care Council, Learning Disability Awards Framework, National Initiative on Autism: Screening and Assessment – NIASA)
- mail out information on external training events, for example, by becoming corporate members of the National Autistic Society
- encourage agencies to maintain staff training records and include specific mention of autistic spectrum disorder within their training policies
- maintain contacts with practitioner interest groups, for example an LEA working party on autistic spectrum disorder.

### Training principles

Training programmes for each service should be written following the audit in consultation with their respective services’ training department.

1. There will need to be expert consultation in developing the content of both awareness sessions and job specific/specialist training, for example, the National Autistic Society Training and Consultancy Service.
2. Generally there will be two tiers of training – awareness sessions and job specific/specialist training.
3. No job-specific/specialist training should take place before awareness sessions.
4. The programme for each service will include how often training needs to be repeated and who is responsible for organising it.
5. Trainers need to be experienced, good communicators and preferably still working alongside people who have autistic spectrum disorders.
6. Training should be built into the working day – not an optional extra, or during unpaid staff time.

***The most common service request of adults with Asperger syndrome is for support from someone who understands their condition.<sup>13</sup>***

***In order to provide a good service for people with autism it is necessary to understand their needs. Understanding of their needs must be based upon detailed knowledge of their disabilities.***

(Wing, 1993)

<sup>13</sup>Avon Asperger Syndrome Project 1999-2002.

7. Cascading information from training should be avoided, where possible, due to the complexity of the subject matter.
8. Consideration should be given to providing outreach/community based trainers who can work with day and residential services to develop staff practice with individuals they are currently supporting.
9. Some local authority training departments may need to receive awareness sessions on Asperger syndrome before they start to commission training, so they can understand the reason for impairment specific training.
10. Independent sector providers should be kept up to date about training events, and encouraged to take up training opportunities.
11. Individuals with Asperger syndrome and parents should be paid to contribute to training programmes.
12. The provision of regional training resource centres for families and professionals should be considered. Often local Branches (parent support groups) of The National Autistic Society have good libraries to offer information.
13. The Planning Group could maintain or start up a local professional network to share good practice, information and advice. This might include contact details as well as areas of particular interest.
14. The Planning Group may wish to affiliate to the Asperger Syndrome Professionals Network (ASPEN), a support group for professionals working with people who have Asperger syndrome.<sup>14</sup>
15. Links should be made with universities to develop academic accredited training courses.

## Awareness sessions

Awareness sessions should be made available to all staff in contact with adults who have Asperger syndrome and require basic understanding of the condition.

Awareness sessions provide an outline of the theory of autistic spectrum disorders and give those being trained a few basic practical strategies they can actually use in their work. But above all, staff should go away from the awareness session with some better sense of what it is like to be autistic in a 'neuro-typical' world.

The content and style of delivery of the awareness sessions is important and expert consultation should be used. The format for awareness sessions should include:

- an introduction to autism (what it is and is not, causes, prevalence)
- the concept of the autistic spectrum (differential diagnosis, high functioning/Asperger syndrome)
- the triad of impairments, with examples of behaviour
- how people with Asperger syndrome view the world
- cognitive style and emotions
- additional differences (sensory, motor)

<sup>14</sup>Appendix B.

- practical responses
- sources of further information, advice and contact numbers.

It is unlikely that the necessary material can be covered in less than two hours. Three hours is comfortable for most services. This allows for a break, use of video and questions.

Awareness sessions should use 'whole system' approaches wherever possible, involving all staff in organisations (for example, awareness sessions in schools would include administration, lunchtime supervisors, reception, teachers, teaching assistants, senior staff, school nurse/counsellor, governors). This may require several awareness sessions at different times and on different days to ensure all staff can make one of the training events.

Opportunities for joint awareness sessions should be encouraged by the Planning Group where it will enhance multi-disciplinary understanding. For example, offering joint sessions to probation, youth offending and police.

## Job specific and specialist training

Job specific/specialist training should be developed in consultation with the Planning Group, and other agencies such as National Autistic Society Training and Consultancy service.

Training requirements need to be carefully researched in order to be of use to staff. Therefore staff evaluation of the awareness sessions should include questions not only about the content of the session but also identify further training needs.

Ideally time set aside for a separate consultation exercise may elicit the precise learning needs of staff and make training more valuable.

Some of the more regularly requested areas for training may include: how to help someone develop a better understanding/expression of sexuality; motivation of someone who is reluctant to access any services; managing aggression; mental health aspects; supporting people into jobs; supporting students in continued education settings; how to offer emotional support; helping someone who is very withdrawn.

Whilst much training will need to be specific to each agency, wherever possible the Planning Group should encourage joint funded job specific training opportunities to make training cost effective and develop multi-disciplinary understanding.

Most job specific training will take between one and three days.

## Good practice – job specific training for community workers

Training for community workers (including social workers and community psychiatric nurses) needs to be thorough and should encompass the following topics.

1. Cognitive/developmental/genetic theories.
2. The development of Asperger syndrome through the life span including presentation in adulthood.
3. How to engage/interview people with Asperger syndrome.

**‘Social workers seem to run scared of him. I think they lack the confidence.’**

**(Parent, South Gloucestershire)**

4. How people with Asperger syndrome make choices and express wishes and feelings – person-centred planning.
5. How to offer and structure emotional support.
6. Relationships, sexual understanding.
7. Practical life skills.
8. Vulnerability factors, social naivete, duty of care, acceptable risks, informed choice.
9. Working with parents/significant others and assessment of carers’ needs.
10. Working with partners.
11. Parenthood, and child welfare issues.
12. Drug (including alcohol) misuse.
13. Co-morbidity, mental health, reducing depression.
14. Managing and reducing aggressive behaviour.
15. Supporting people with Asperger syndrome whose motivation is low.
16. Support into employment/continued education.
17. Aspects of criminal justice system, working with the police, ‘appropriate adult’ role and giving evidence.
18. Links – who to approach for more information and local/national resources.

### National perspective training recommendations

There is a need for national consistency in training standards (see NIASA, draft 2002). There should in time be an autism training policy from the General Social Care Council (GSCC), which local authorities can align themselves with, as well as an NVQ in autism, or use of the Learning Disabilities Awards Framework (LDAF).

Information/modules on autistic spectrum disorders should be part of relevant undergraduate and post-graduate training in health and social services professional training.<sup>15</sup>

<sup>15</sup>See *Good Autism Practice*, May 2000, for details of universities offering courses in autism.

## Who will require training on Asperger syndrome?

The local services training audit should include at least the following:

Residential and day services local authority workers (mental health/learning disabilities)  
 Social workers (adult duty)  
 Social workers (mental health/learning disabilities)  
 Community care workers, and similar outreach support staff (mental health/learning)  
 Supported housing staff  
 Foster carers (including short break carers)  
 Residential care staff (mental health/learning disabilities)  
 Day care staff (mental health/learning disabilities)  
 GPs  
 Primary care and other counsellors  
 Occupational therapists (mental health/learning disabilities)  
 Speech and language therapists  
 Educational psychologists

Clinical psychologists/assistant psychologists  
 Psychiatrists  
 Community psychiatric nurses  
 Child and adolescent services  
 Teachers  
 SENCOs  
 Teaching assistants  
 Further education learning support staff  
 Further education tutors  
 Local university disability units  
 Disability Employment Advisers (DEAs)  
 Occupational psychologists  
 Connexions Personal Advisers  
 Connexions specialist Personal Advisers  
 Training providers for young adults  
 Youth and community workers  
 Young persons adviser (*Children Leaving Care Act 2000*)  
 Probation, youth offending teams, prison staff, police

## Support pathway for community care assessment

It is important that local authorities establish a clear route for families to access assessment of need under *The NHS and Community Care Act 1990*, for individuals requesting support.

The first essential decision of the Planning Group senior manager will be to decide which team(s) provides community care assessments of need for people with Asperger syndrome.

These are some of the options available:

1. Social services mental health teams (for example, Bath and North East Somerset).
2. Social services learning disability autism specific social workers (for example London Borough of Harrow).<sup>16</sup>
3. Social services learning difficulties teams.
4. Generic adult care team teams.
5. Joint health and social services trust teams.
6. A combination of learning disability and mental health teams and sometimes generic adult care teams (the current situation in most authorities).

### Good practice – community care assessment of need (Bath and North East Somerset)

Bath and North East Somerset (unitary authority) has three types of adult social services teams – mental health, learning disability and ‘generic’/duty. Until recently people with Asperger syndrome were not given any clear information about how to access community care. This has caused difficulties in service development and training as no one has taken overall responsibility. Senior staff struggled to support their social workers, who in turn have felt under-qualified to tackle some of the more complex needs of this group.

*In 2001 a decision was made by a senior mental health manager to resolve this lack of protocol. Mental health social services teams now take the lead responsibility for community care assessment and work is in progress to ensure health colleagues in the Avon and Wiltshire Mental Health Partnership NHS Trust are able to support this work.*

A GP guide to adults with Asperger syndrome has been launched to increase awareness and clarify referral routes.

Generic adult duty teams have been briefed on their role: to refer on to the relevant local Community Mental Health Team (social services) who will carry out the community care assessment of need. Awareness sessions are planned for the duty teams, so people who contact for support will be appropriately referred.

***‘...providing a seamless service to users and carers, is one of the fundamental objectives of The NHS and Community Care Act 1990.’***

**(Social Services Inspectorate, SWSG 1991b)**

***‘Mental health and learning disability units spent months trying to decide who was responsible for him – meanwhile his condition got worse.’***

**(Parent, Bristol)**

***It will often not matter whether learning difficulties, generic adult care, or mental health team(s) take the lead on assessment what matters is that someone does take responsibility!***

<sup>16</sup>Other social workers in the team also work with people with autistic spectrum disorders, but one social worker develops expertise and carries the more complex cases.

**‘I wish they would make up their minds about what I am.’**

**(Person with Asperger syndrome)**

### ...continued

An information resource is to be held by social services so that when people contact them, they can provide lots of relevant signposting information on a range of topics including adult diagnosis, colleges, employment, support groups, welfare benefits and local counsellors.

This information resource will be useful whether the Community Mental Health Team can or cannot provide statutory services, following assessment of need.

The Community Mental Health Teams in Bath and North East Somerset have received awareness sessions on Asperger syndrome and further job specific/specialist training is being provided.

*The decision for Asperger syndrome to come under the community mental health team has reduced uncertainty, allowed staff to receive training and will pave the way for effective service development.*

## Social services and health must work together

The decision about who will take lead on assessment for community care will require consultation with health colleagues. Having decided which social services team will carry out the assessment, the Planning Group should work closely with health colleagues to establish a support pathway.

For example, if mental health social services teams decide to complete initial assessments of need for community care, then mental health (NHS) workers, including psychiatry, should complement and support their work.<sup>17</sup>

This health and social care approach will become easier as joint care trusts develop.<sup>18</sup>

## How will people with Asperger syndrome request an assessment?

The easiest option for people wishing to request an assessment of need is for local authorities and health trusts to supply a single point of entry – one telephone number/address.

Local authorities should supply a single point of contact to all requests for assessment of need. The point of contact will be well advertised in information produced by the Planning Group or other organisation, and known to all health and social care teams and professionals, including primary health.

Across the four Avon<sup>19</sup> authorities there are ‘adult care duty desks’ which act as a single point of entry into community care assessment. The adult care duty social worker takes the referral and it is then decided which is the most appropriate team to arrange a community care assessment.

Ideally each local authority should designate one team to deal with the referral.

## Principles of good community care assessment

1. Assessment of need is a legal duty under *The NHS and Community Care Act 1990*. It is dependent on appearance of need, not consent for assessment. This is an important principle in relation to engaging with someone who has Asperger syndrome. Whilst consent should be sought and rapport developed appropriately, ultimately there will be occasions when the person may find it difficult to engage in a co-operative way.

<sup>17</sup>In some areas NHS professionals who are willing to see people with Asperger syndrome have encountered the opposite difficulty – social services colleagues not willing to provide community care assessments of need for people with Asperger syndrome.

<sup>18</sup>Somerset Partnership mental health trust is a good example of joint working arrangements for adults, where a few Approved Social Workers (ASWs) are specifically assigned to work across learning disability and mental health. Cheshire and Wirral Partnership NHS Trust is another example of a combined function trust, which it is hoped will cover all ages across learning disability and mental health services.

<sup>19</sup>Avon is the old county name for four unitary authorities Bath and North East Somerset, Bristol, South Gloucestershire and North Somerset.

2. Assessment should be pro-active. Active intervention is often required to enable the person to be independent enough to make their own informed decisions about whether they wish for support.
3. People with Asperger syndrome may find it difficult to engage in the assessment process for a number of reasons. All of the following factors need to be considered in order to create a meaningful assessment process:
  - a wish to avoid any new social situation such as meeting a social worker, due to anxiety
  - wishing to 'fit in' and not want others to know about their difficulties or be 'labelled'
  - having limited insight and understanding of their own emotional needs
  - sensory/perceptual processing or concentration difficulties impacting on their ability to attend to questions
  - being unable to process too much verbal information
  - depression
  - 'inflexible'/'black or white' thinking
  - not understanding what assessment means
  - attempting to say the 'right thing' and so minimising their difficulties
  - not understanding choices
  - being unable to imagine (and therefore discuss) what independent living means unless they actually see it.
4. Ability to engage is itself a tool to gauge what sort of service may be most appropriate.
5. People will often mask their difficulties for a number of reasons, so care managers need to take care not to assess someone as more capable of independent living than they are. Without a network of family and other informal support many 'capable' people would end up in statutory services in a crisis state.
6. Although the presenting need might be 'support at college' or 'finding a job', careful assessment should be made of other areas of functioning. Often people with Asperger syndrome will cope with college or work, but require some low level ongoing home support to achieve or maintain this.
7. Working with parents is an important and sometimes complex area. Social workers need to understand the central role parents often have in relation to assessment, and listen closely to what they say. Indeed it will often be the parent who initiates the referral. Parents should be partners in the assessment process, unless there is good reason why they are unable to contribute.
8. Sometimes parents will find it hard to 'let go'. However, more often parents are willing to 'let go', but not until appropriate service provision has been set up, as they know they will have to 'pick up the pieces' if things go wrong.
9. Occasionally parents may have Asperger syndrome themselves or similar difficulties. This needs a sensitive approach.
10. People with Asperger syndrome can be easily confused by care professionals' tendency to 'talk around' a subject or issue. Whilst it is important to have discussions about topics of relevance to the person, it is equally important to use clear and direct language and avoid vague speculation and ambiguity.

11. Comprehensive early assessment can help to avoid expensive mental health placements and treatments later in life. The person with Asperger syndrome may have a very uneven profile of ability. Assessment can take several months to 'complete'. Care managers and team managers need to be aware of this. However the time used building a relationship is well spent, as the worker will better understand the individual's needs. It also means that support costs are kept to the minimum.
12. Keeping people informed of the assessment process will be important for many people with Asperger syndrome. Writing to let people know of the likely waiting time before assessment, what happens during an assessment and explaining eligibility criteria for services is useful. Anticipated delays in the process should be explained from the outset.
13. Children with autistic spectrum disorders become adults with an autistic spectrum disorder. Assessment needs to look at long-term support needs, as many people with Asperger syndrome will require life-long, ongoing assistance into older age to maintain whatever level of independence has been achieved.
14. The types of support may vary but the core needs will tend to remain. People may become more able, but assessment must attempt to differentiate between skills which can be maintained without help and those which will always require prompts or support.

## Written assessment of need

*'All assessments are likely to be recorded on some kind of pro forma ... A copy of the assessment of needs should normally be shared with the potential user, any representative of that user and all the people who have agreed to provide a service.'* (Social Services Inspectorate/SWSSG 1991a p. 56).

The assessment of need should be presented in a clear written form for the person with Asperger syndrome and significant others. Care needs to be taken with how information is shared with the person, avoiding over lengthy verbal explanations that can confuse. Some people can react badly to written words construed as 'negative'.

The assessment will need to be written in an unambiguous and positive way and may require the social worker to go over the material in the assessment with the person.

## Information and advice

Where an assessment of need has shown that the person does not meet eligibility criteria for community care, the social worker should still provide information and advice about other services.

The social worker should discuss with the person whether support from Connexions, the Employment Service, The National Autistic Society, voluntary agencies and other sources would be useful, and ensure the person is linked into those services.

Contacts for alternative sources of support should be available in an easily understood format – an information resource for families affected by Asperger syndrome.

## Written care plan

Where the assessment of need leads on to a care plan, the social worker should produce a written document in an accessible form:

*'Except where no intervention is deemed necessary, this assessment record will normally be combined with a written care plan setting out how the needs are to be addressed...'* (Social Services Inspectorate/SWSG 1991a p. 56).

The wording of the care plan should be carefully considered to help reduce anxiety. It needs to be clear, avoid uncertainty, take account of the person's ability to manage change and any mental health considerations.

## Good practice – a framework to working with people who have Asperger syndrome (SPELL, National Autistic Society)

The National Autistic Society SPELL framework is used to inform autistic spectrum disorder good practice across individual, service and organisational settings. It is not a rigid structure but rather a list of five important areas that need to be considered carefully when working alongside people with autistic spectrum disorders.

If a person with Asperger syndrome is having difficulty in a particular setting it is highly probable that he or she is having difficulty with one or more of these five areas. By considering each area in turn, it becomes possible to identify where the individual's needs are not being met, decide on action to resolve the difficulty and bring about positive change.

**STRUCTURE** means enabling the individual to predict events, so as to reduce anxiety. It is recognition that open-ended choice creates anxiety.

**POSITIVE** means a positive approach, and having expectations the individual will achieve. It involves building on strengths, and enhancing self-confidence and self-esteem.

**EMPATHY** means seeking to see the world from the person's unique viewpoint.

**LOW AROUSAL** means utilising a calm, focused, planned intervention, with the removal of clutter and distraction. It involves using a non-confrontational style, with supported rehearsal of potentially aversive tasks, or events.

**LINKS** means maintaining partnership with relatives, agencies and any other appropriate support mechanism. It is achieved by inclusion and accessing 'mainstream' opportunities.

## Service provision

**'We'll be doing all this good assessment but still have nowhere for him to go ...no services.'**

**(Social worker, Bristol)**

**There are some adults with Asperger syndrome who find it hard to leave their bedrooms, let alone their homes, so services need to be adaptable.**

**People with Asperger syndrome are often unable to access 'ordinary public services.'**

**(Knight and Porter, 2001)**

<sup>20</sup>National Schizophrenia Fellowship drop-ins have been cited as useful to people with Asperger syndrome.

<sup>21</sup>Herts Careers Service – Stop Gap project has a drop-in as well as a more formal programme for young people with Asperger syndrome – Appendix B.

<sup>22</sup>Breakthrough in Clevedon- Appendix B.

### How and where services need to be delivered

The Planning Group in each local authority should look to encourage development of flexible, accessible services as outlined in the following section. Some services are already aware of the need for pro-active support, for others this will require training.

#### Flexible outreach

There need to be outreach workers to engage and develop trust with those people who are not able to come to a service.

This outreach approach will often be necessary for people who are wary of services, dubious about the benefits of support, or just low in 'motivation'. The outreach may need to consider using a series of short visits to build up contact or visit the parents/family for a time, until the person is ready to talk to the worker.

It is important to be honest about the purpose of involvement but communication of purpose is equally important to get right. Some people may respond to a gentle approach: 'I am visiting you to find out if I can be of any assistance and to tell you a bit about supported housing.' Others will prefer a more direct style: 'I have come to help you find somewhere else to live'.

*This is why gaining prior information about an individual's preferred method of communication is good practice.*

Spending time getting to know the person is vital for establishing trust and also for developing insight into the complex personality of someone with Asperger syndrome. It may take considerable 'outreach' before someone is ready to try out a community service.

#### Drop-in facility

Drop-in type facilities<sup>20</sup> may work quite well for some people with Asperger syndrome. These require staff that understand the condition, and can help the individual 'orientate' him or herself to adult life.

A drop-in acts as a sign-posting service for individuals and gives initial information on continued education, employment, community care, health care, diagnosis, and social support. It is possible that the worker could be from a local community care team, or Connexions (for clients under 25)<sup>21</sup>. Joint funding options should be explored for this type of post.

In North Somerset a mental health base is used once a week as a drop-in facility and professionals come to the people with Asperger syndrome, to give advice and information in a relaxed setting.<sup>22</sup> For example, it could be that a young person would be happier talking in a group to a social worker about housing in the future, but not in front of his parents at home to begin with.

### Using routes and venues already established by voluntary groups

Local authorities should make constructive links with the National Autistic Society, autistic societies and other parent/user/voluntary groups. People with Asperger syndrome may be more able to accept a statutory service if it is facilitated by an informal network of support such as a voluntary group.

As it is usually voluntary groups providing services that the local authority has failed to establish, statutory services should make formal links with local groups and societies to develop and fund quality initiatives.

### Advocacy service

Because of the difficulties accessing ordinary public services, a skilled and adequately trained advocacy service would be of great benefit to families and people with Asperger syndrome. The advocacy service will need to be aware that making choices, interpreting feelings into purposeful action and defining goals can be a complicated process for some people with Asperger syndrome.

### Development worker

It will be useful for local authorities to consider employing an Asperger syndrome project or development worker. This person could facilitate interaction between the individual and services as well as offering advice, information and training.

Such a post would also facilitate and maintain a multi-disciplinary working perspective, (Hand, 1999) and the worker would use some hours researching funding for joint initiatives (Jarrett, 2000).

Examples employing development workers include North Yorkshire County Council and Leicester City Council; Lothian Primary Care NHS Trust has an autism co-ordinator to develop managed clinical networks.

## Good practice – development work across four unitary authorities (Avon Asperger Syndrome Project)

The experience of the Avon Asperger Syndrome Project has been that just one worker can have a great impact across four unitary authorities. The Project Officer in Avon was funded by the Department of Health to research the service needs of adults with Asperger syndrome, develop multi-disciplinary working in Avon and report on good practice nationally.

The 3 year project delivered awareness sessions and job specific training to approximately 1000 professionals and parents; telephone advice to over 400 professionals/parents; casework to approximately 20 families and produced an 80 page information resource for families on services for adults with Asperger syndrome.

A college course was set up for adults with Asperger syndrome and a joint social skills group with the local Bath and North East Somerset Primary Care Trust (learning disability).

Ongoing social groups for approximately 40 adults with Asperger syndrome have been set up in Bristol, North Somerset and Bath and North East Somerset. For some adults who attend it is their only social contact.

Whilst the Project Officer was in post a local authority developed a community care protocol for people with Asperger syndrome, backed up by training and a GP guide to adults with Asperger syndrome.

## ...continued

Asperger syndrome planning groups were set up across four unitary authorities, involving multi-disciplinary groups of approximately 80 professionals and the profile of the condition raised in the area as a whole.

*Local authorities and health trusts should consider joint finance for a project worker to audit and develop service provision.*

## Practical support services

Local authorities need to offer support to people with Asperger syndrome, concerning practical life skills.

Support may be in a group or undertaken as individual work, and may vary from intensive intervention to occasional visit. The support could be received from an outreach service, in a residential care home or as part of a specialist further education course.

Often an independent living skill will need to be taught in the actual place where the person lives and will be using that skill, because people with Asperger syndrome may find it hard to generalise a newly learnt skill even across similar settings. This ability varies and should be considered when offering practical teaching/guidance.

Some people with Asperger syndrome will require life long support to acquire some of the following 'skills'; others will often require a 'prompt'; many others can achieve these with minimum support and become independent.

Practical support services will need to address some or all of the following needs for independent living.

1. Financial (for example, budgeting, paying bills, assessing values, dealing with door salesmen, saving money).
2. Morning routines (for example, early morning call, waking and getting up, washing, choosing appropriate clothes, grooming, personal hygiene, self presentation).
3. Organisation and reminder systems (for example, weekly timetables, note keeping, maps, using a mobile phone, useful telephone numbers book, keeping appointments, calendar).
4. Food hygiene (for example, cleaning the fridge, checking sell-by-dates, cooking at the right temperature).
5. Diet (for example, understanding of a balanced diet, remembering to eat and drink enough and to exercise).
6. Avoiding loss of personal possessions (for example, crime prevention awareness, not leaving possessions unattended, not lending items to strangers).
7. Home safety (for example, locking up at night, not leaving the gas on, shutting windows, when to ask for assistance).
8. Home skills and maintenance (for example, cooking, dealing with uninvited guests, changing a plug, ironing, washing up, adjusting to seasonal changes, unblocking a sink, heating, doing the laundry, putting rubbish out, when to ask for assistance).
9. Personal care (for example, reporting illness, medication, hygiene, sexual health, getting enough sleep, how to relax).
10. Community skills (for example, using pubs, cafes, clubs, taxis, letting someone know

**Only 3% of people with Asperger syndrome are living fully independently.**

**(Barnard et al, 2001)**

**Lots of parents complain that whilst schools and colleges are geared up for getting young people through examinations, they are less good at developing the skills that their sons and daughters need to survive socially. Many leave school with a few GCSEs, but unable to answer the phone, cook a basic meal, hold a conversation, or cope with money.**

whereabouts, using public transport, using libraries, driving lessons, basic manners, avoiding risk situations, how to explain Asperger syndrome to others, how to say 'no', awareness of own behaviour, reporting incidents, dealing with neighbours, useful conversation topics with acquaintances, personal disclosure, not 'staring', asking for help).

11. Understanding and applying for welfare benefits (for example, Job Seekers Allowance, Housing Benefit, Income Support, Disability Living Allowance, Incapacity Benefit), assistance with form completion, and links with knowledgeable professionals in the Employment Service.

## Relationship support services

Local authorities and health trusts need to offer support to people with Asperger syndrome concerning relationships, to improve quality of life, prevent social isolation and to act as a counter to mental health difficulties.

A range of services is required – low level support to facilitate more social contact through to specialist services. The training, understanding and experience of staff are crucial to success.

Some relationship support may lend itself to group work, some of it should be done individually. Where group options are identified as most effective, there will be a need to assess whether the group is just for people with Asperger syndrome or a more general group. Self reported benefits seem to occur for most people who meet others with Asperger syndrome, but others prefer not to mix with those who have the same diagnosis.

The audit will highlight services currently existing which just need more Asperger syndrome awareness as well as services that will need to be specifically commissioned. For example, existing befriending schemes may simply require some training in autistic spectrum disorders. Social groups for people with Asperger syndrome may not be in existence so will need to be set up from scratch.

The following are just some of the services required.

### Individual support to reduce social isolation

Individual support may be needed to link into existing community activities, interests, clubs, leisure facilities and to help the person identify social networks.

Some people find groups too daunting and prefer to have one-to-one support, until they can cope with community settings. Some people will always require one to one support to access group settings.

Voluntary befriending schemes<sup>23</sup> can work well because they are often more flexible than statutory schemes, subject to fewer time restrictions, and are very cost effective. It is important for staff to be aware of their role as ‘befrienders’ and communicate this clearly to those they work with.

Services must be aware that ongoing support may be required to help someone build up and also maintain social contacts.

### Individual counselling and psychotherapy

Many people with Asperger syndrome suffer from mental health difficulties. Counselling may be helpful but it does seem that certain styles of therapeutic intervention may be less beneficial. Any therapy that treats the core symptom(s) of Asperger syndrome as an emotional issue will be counter-productive, as will therapists and counsellors who do not understand the psychological theories of autistic spectrum disorders.

Cognitive-behavioural approaches have been cited as a potentially useful tool to use with some people who have emotional difficulties and are willing to work at these using a fairly logical approach (Hare, 1997).

***‘He desperately wants to live in the community but he is so socially gauche that he is laughed at, picked on and has even been attacked at a bus stop in the daytime.’***

**(Parent)**

***‘I can’t say enough about his Youth Worker. He has worked really hard helping him in ways we as parents wouldn’t be able to. He explores... social situations with him, even accompanying him to various places. He talks through issues-girls, relationships, sex, alcohol and drugs. Daniel really looks up to and listens to him.’***

**(Parent, Berkshire)**

<sup>23</sup>The National Autistic Society has a volunteer befriending network across many areas of the country – see Appendix B.

***'He has no self initiated hobbies or interests ...(he now) receives a piecemeal, mish-mash of activities provided by a variety of people who have no experience of Asperger syndrome and at very irregular times ...'***

***(Parent, North Somerset)***

The particular cognitive style of the individual will need to be assessed, so that realistic appraisal can be made of the person's likely ability to change. This is not necessarily to say people with Asperger syndrome have less ability: they may make long-term positive changes, due to 'rigid' thinking.

Specialist counselling approaches will be required for assisting people with drug/alcohol problems. Some people 'self-medicate' with alcohol possibly because they are not receiving appropriate support: drinking becomes a means of 'damping down' social anxiety.

Some people with Asperger syndrome have been led into addictions as a result of locating and mixing with a social group who they believe to be more 'accommodating' of their social differences.

## **Psychiatric intervention**

Psychiatry has an important role to play in supporting people with Asperger syndrome, in providing diagnosis, assessment, medication, support structures, advice about psychotherapy and management of those who are a risk to self or others. Asperger syndrome is not an illness that can be treated, it is a lifelong disorder and requires a long term support model, which psychiatrists need to be aware of. Secondary illness may be recurrent unless the needs arising from the underlying syndrome are addressed.

Medication has its place alleviating anxiety, depression or other problems but some long term change often requires a wider perspective to be taken. Ensuring consistency, structure, low arousal and empathy will require assessment of the person's whole lifestyle and environment. (Shah, 1999; Howlin, 1997; Carpenter, 1999).

## **Psychology services**

These services can be of great value providing psychotherapy, behaviour management advice, information and support to families. It will be useful for psychologists to develop understanding and evidence-based approaches to work, so as to offer alternatives to medication treatments. Both psychiatrists and psychologists may be especially useful when people with Asperger syndrome develop motivation difficulties, aggression, extreme passivity, depression, anxiety and other complex difficulties (such as co-morbidity and dual diagnosis).

## **Social groups<sup>24</sup>**

These seem to be of great benefit to many. It is important for people to know they have somewhere they can go, feel relaxed and be themselves without criticism; to have the opportunity to be in the company of those who have similar needs and approaches to life. These groups give opportunity to develop social relationships and activities, usually in a fairly informal atmosphere, often with no specific agenda, although some structure must be provided, even if just in terms of 'what to expect'.

It is better if social groups are long-term wherever possible, since the need for social contact is usually relatively stable and the groups appear to be very beneficial for those who choose to attend.

Social groups will sometimes develop into other types of group or highlight a need for other interventions, such as a discussion group on relationships, or a group to learn practical independent living skills.

<sup>24</sup>There are social groups in Birmingham, Sheffield, Leicester, Northamptonshire, Manchester, Norwich, Cambridge, Bristol, North Somerset, Nottingham, London, Surrey and elsewhere.

## Good practice – setting up social groups<sup>25</sup>

It is important to think through the following issues if setting up a social group, so that it is well-organised and unnecessary difficulties avoided. The items to consider are aimed at social groups, which tend to be fairly informal, but will be appropriate for many of the other groups discussed in this section. Facilitators should consider the relevance of each item for his or her group.

### Terms of reference

Purpose of the group  
 Objectives of the group  
 Membership – gender, age range, ability, formal diagnosis  
 Open or closed group?  
 Referral process  
 Catchment area  
 Lifespan of the group

### Important legal and ethical issues

Confidentiality and statutory responsibilities  
 Duty of care statement  
 Ground rules  
 Assessment of risk regarding vulnerabilities of members  
 Accountability  
 Insurance/liability of facilitators and volunteers, for example transporting members in own cars  
 Insurance for members.

### Practicalities

Funding  
 Day of week and time of meetings

Duration and frequency of meetings  
 Safe and accessible venue  
 Transport of members  
 Advertising of group and keeping members informed, for example, by a newsletter  
 Structure and content of meetings  
 Links to local autistic spectrum disorder groups.

### Assessment and evaluation

Referral/assessment format for new members, for example questionnaire  
 Matching members – for example by self selection, interests, general intelligence, social ability, personality  
 Managing new members, expectations of the group  
 Members' committee  
 Reviewing individual members' progress  
 Reviewing group progress  
 Information on members for example name, address, contact numbers, GP, medication  
 Monitoring unrealistic expectations  
 Exclusion of incompatible members  
 Comments and complaints procedure  
 Pre and post-evaluation of group efficacy  
 Evaluation measures – enjoyment, attendance, behaviour, skills acquired  
 Different methods to measure members' satisfaction.

### Facilitators and volunteers

Experience and training of facilitators  
 Number of facilitators and volunteers  
 Training, expenses and clarity of role for volunteers.

## Discussion groups

These may be a little more structured in order to talk through specific topics, such as difficulties at work, college or in relationships. They may be an option for those who wish to develop social contacts but are unsure how to go about it, those who are struggling with relationships and those who find more 'informal' groups difficult.

## Interest groups

This sort of group may be of value to people who have special interests which they can share. An example might be setting up a computer club at school, or chess club for a group of adults. These groups provide an opportunity for people to excel at something they are good at. They may also provide sufficient incentive to people who are socially isolated to leave their home and participate in a level of social contact that is comfortable and may lead to greater self-confidence.

<sup>25</sup>The National Autistic Society will be producing some guidelines on the facilitation of social groups – Appendix B

## 'Political' groups

The term political is used loosely to describe groups that exist as service user, or pressure groups. There are a few examples of these sorts of groups and it is likely they will increase in number, as more people are diagnosed and request services to meet their needs.

## Social skills

Structured 'social skills', 'social performance' and 'communication' work. These may be a choice for those who wish to improve their social skills in a more direct way than in the discussion groups. Sometimes discussion groups may develop from more structured 'social skills' groups (for example, as in the West Midlands Autistic Society). These groups have some successful outcomes with some individuals (Howlin and Yates, 1999). Whilst these are often group activities, some people may prefer and benefit from some individual work first.

Virtual social skills training may be a method of use to some.<sup>26</sup> This involves using computer simulations of everyday social situations that someone with Asperger situation may encounter. The person can use the training package to learn appropriate actions and communication from the safe learning environment of a PC. By developing skills in these simulated situations, an individual's confidence may increase, reinforcing social understanding in 'real life' settings.

Some people will always need to learn social skills in the actual place where those skills are required. Others will need to rehearse imminent social situations where a particular skill is to be displayed, but can then usually carry out the skill unaided ('social stories' or similar may be of use here) and some will require considerable verbal prompts to produce a socially acceptable response.

## Speech and language therapy

This service is in high demand and few people with Asperger syndrome seem to be able to access this. Some speech and language therapists run communication groups, which may be of great assistance, especially for those who find it hard to talk out loud. Group work and advice giving may be one of the most effective uses of time. It is important for speech therapists to consider all aspects of communication in their work especially with those more able and 'fluent' in language.

<sup>26</sup>Contact The National Autistic Society information centre about an example of this research at Nottingham University called VirArt.

## Good practice – an independent living skills and social group (Monday Club, Leicestershire Autistic Society)

The Leicestershire Autistic Society's Monday Club has been running since 1998, following the success of an initial pilot group. It is a club for over 18s with a diagnosis of Asperger syndrome. The club meets at a city centre YMCA and has a mixed sex membership of about 32 people. There is currently a short waiting list.

The group meets most Monday evenings between 7.00 and 9.00pm during the year (4 blocks of 10 weeks) and 15-18 people attend on an average night. The group has a mixed programme that members devise with the assistance of two paid staff and 3-4 volunteers. The programme has activities such as computer skills, budgeting, cooking, first aid and other life skills. It also

includes community social events such as pub nights, cinema, bowling, playing pool and some group members have had a weekend away together.

*Joint funding for the group has come from Leicestershire Health Authority and social services – Leicester City Council, Leicestershire County Council and Rutland County Council.*

The aim is to provide a safe, positive environment for adults to develop confidence in social skills, independent living and build relationships with one another. Members are very supportive of one another and share difficulties in order to solve problems and reach solutions. Those who

**...continued**

have been through a particular stage, such as college or are in work, give advice to the others.

People have used the group to develop living skills, enabling some members to move from residential care to a more independent lifestyle. The group is always there as a base but a number have 'moved on' appropriately and now visit the group more in a social capacity.

*The benefits to the funding local authorities and health authority are reduced mental health difficulties and reduced support costs as people are learning skills to help themselves in independent living.*

**Relaxation**

Some people find activities, such as tai chi, yoga, massage, and aromatherapy useful, especially those who find it hard to 'unwind' and de-stress. Many people with Asperger syndrome report feeling stressed a lot of the time and some find it hard to relate to the idea of relaxing. Support may be needed to find a suitable method of de-stressing. For some they may simply require 'permission' to have more time away from the demand of social contact.

**Physical activities**

Walking, climbing, keep fit, team and individual sports. Exercise has been promoted by many as particularly valuable for people with autistic spectrum disorders, as it often reduces stress.

**Creative therapies**

Activities such as drama, music, or art therapy do not seem to be offered to many people with Asperger syndrome. This is unfortunate since they would seem to offer potential value in helping people with emotional difficulties and verbal communication difficulties express themselves (Peter, 2000). Drama therapists (or actors, with group experience) are sometimes employed to lead social skills groups with various aims including the development of verbal and non-verbal skills, social awareness, and self-confidence. (Asperger Norfolk, SAFE).

**Disability and self-awareness**

People with the diagnosis may not have much idea about what Asperger syndrome is, and many social groups have spent some time discussing the condition and how it affects them. Some adults ask: 'What is me and what is Asperger syndrome?' and this too may need discussion. Work may need to be done individually, then later in groups, but it will vary.

Discussion is often helpful because many people with Asperger syndrome still blame themselves for things that are outside their control. Conversely some people may experience a loss of control following diagnosis and need encouragement to think and act more positively. Discussion will allow time for feelings to emerge. There may be a lot of anger about past events, especially if the person suffered due to late diagnosis. Some will not wish to discuss the diagnosis at all. If group work is undertaken workers need to be aware of the depth of feelings that may be expressed.

As with counselling or any work that involves emotional disclosure, adequate preparation should be made by those running such groups.

## Post-diagnosis groups

These may be useful for small groups of recently diagnosed adults to meet and discuss their diagnosis and what it will mean for them. There are likely to be a lot of questions and emotional responses, for which facilitators must be prepared. These groups could develop into general discussion or social activities groups.

## Self-advocacy and assertiveness

Self-advocacy, confidence building, personal development and assertiveness courses may be beneficial to some people. Many people with Asperger syndrome have difficulty with giving a measured response to situations when they need to 'state their case'. They are either too aggressive or too passive. Koning and Magill-Evans (2001) found that young people with Asperger syndrome identified a lack of assertion skills as the area they were most aware of, so courses could be of value.

## Asperger syndrome chat rooms and email lists

Whilst not a local authority service, it is important to be aware of the value of such communication as people with Asperger syndrome may not know about the groups. There are a number of on-line discussion groups, usually run by and for people with Asperger syndrome.

People with an autistic spectrum disorder may find this sort of contact exceptionally useful. Some people prefer to be able to communicate with others without the added complications of eye contact, and body language. The fact that generally the communication only involves people on the autistic spectrum may help in the development of positive identity.

## Emotional understanding and expression; anger and conflict management

Most adults with Asperger syndrome have difficulties with emotional understanding and expression. They may require support to develop understanding of emotional expression in others. For example, people can often become stressed because they take 'comments' as 'criticism', so support may be about ways to deal with this tendency to over-react.

People may require professional help in understanding their own emotional system – such as recognising symptoms of stress or anger before they reach 'overload'. Some people will benefit from talking about their feelings in a group, others will require or prefer to talk individually about techniques to understand and express emotions in a healthy way.

This type of support is about helping people with everyday understanding and management of their feelings. For resolution of more entrenched emotional difficulties, counselling or psychotherapy may be more beneficial.

## Understanding close relationships and sexuality

This educative work should be undertaken at school to help people get ready for adult life. Unfortunately most do not receive adequate education about relationships. Whilst some adults choose not to pursue intimate relationships, those who do often remain ill-prepared and have no-one, outside their family, to discuss difficulties with. This type of support will cover a wide range of needs from information and advice, through to relationship counselling. The organisation Relate is identifying more couples affected by Asperger syndrome as awareness increases (Aston, 2001).

Some people may benefit from being able to discuss relationships and sexuality within a small group setting. This is because many adults can feel they are the only ones with difficulties finding a partner and could draw increased confidence from being able to share feelings in a well-facilitated group.

## **Risk assessments**

Assessment will be necessary for people identified as posing risk to self or others (for example, violence to self or others, total passivity, total rejection of society's norms, refusal of food, threats to carry out acts of deviant or dangerous behaviours).

A very small minority of people who commit criminal acts against others will require a specialist approach to meet their needs. This is specialist work that should be undertaken by professionals with experience and expertise in Asperger syndrome such as The National Autistic Society Hayes Unit in Bristol, for adults with Asperger syndrome who are receiving treatment under *The Mental Health Act 1983*.

## Health services

***‘Once someone is diagnosed I can’t really see any role for health services.’***

**(Senior health professional, Avon)**

The diagnostic assessment should be the starting point for the co-ordination of health support to people with Asperger syndrome (Holland et al, 2000). A thorough assessment of need followed by a health support plan, in conjunction with local authority colleagues should be carried out for each person requiring services during and after diagnosis.

Health trusts and local authorities need to ensure that physical and mental health difficulties of people with Asperger syndrome are addressed adequately. Unless these needs are met people may end up receiving inadequate and often expensive crisis interventions at public expense.

Health professionals are of great benefit to people with Asperger syndrome before, during and after diagnosis – providing assessments, giving advice, assisting with independent living, physical difficulties, preventing mental health crises, running groups, helping with personal and sexual health issues, offering counselling/psychotherapy, creative therapies, outreach and in-patient facilities.

The following are priority areas of service need.

1. Awareness sessions should be provided for all health staff in the locality/ trust area, who have contact with people with Asperger syndrome.
2. Information for GPs such as a ‘guide to adults with Asperger syndrome’ should be available and training offered as Continuing Professional Development.
3. GPs need to be made aware of mental health and other difficulties that can occur with Asperger syndrome, and know where to refer people appropriately.
4. GPs need to know more about medication and people with Asperger syndrome in treatment of anxiety and depression. For example, medication prescribed to reduce anxiety may have the opposite effect.
5. Information for hospitals and clinic staff to assist their understanding of how to provide health care for adult patients with Asperger syndrome should be made available. This could take the form of a leaflet explaining how health care procedures may need to be adjusted for someone with Asperger syndrome. For example, booking double appointment times; explaining procedures clearly; how people will ‘present’ on the ward/clinic; possible hygiene and self presentation difficulties; sensory issues – requiring a separate room, being touch defensive; different pain thresholds and medication tolerances.
6. Speech and language therapy should be made available to adults with Asperger syndrome.
7. Occupational therapists should receive additional training on functional assessments and Asperger syndrome, such as difficulties of transferring skills, low motivation and signs of movement difficulties or catatonia.
8. Psychiatrists and psychologists need to have more knowledge of Asperger syndrome, so they can assess for possible diagnosis more effectively, and not treat symptoms alone.

***‘The psychiatrist didn’t seem to realise he can’t switch his Asperger’s on and off.’***

**(Parent)**

9. Psychologists and psychiatrists should use their therapeutic skills to provide individual and group work for people with Asperger syndrome.
10. Psychiatrists should receive advice regarding Asperger syndrome and medication.
11. Psychiatrists and psychologists or other health professionals should provide adequate post-diagnosis support and information for effective management of the condition.
12. Post-diagnostic groups to be set up or 'bought in' to meet the needs of late diagnosis adults.
13. Community psychiatric nurses should receive training in working alongside people with Asperger syndrome.
14. Health professionals could assist with independent living and social groups for adults.
15. Genetic counselling should be made available for families.
16. Occupational therapists should provide individual and group work for adults with Asperger syndrome, around independent living skills.
17. Mental health in-patient unit staff should receive job-specific training on managing people on the ward.
18. Health professionals should receive training in Asperger syndrome and co-morbidity. For example epilepsy, Attention Deficit/Hyperactivity Disorder (or Attention Deficit Disorder), Tourette's syndrome, or other difficulties.
19. Health professionals should receive training in Asperger syndrome and mental health difficulties, such as depression, mood swings; anxiety related problems such as social phobias, irrational fears, paranoia, obsessive compulsive disorder or panic attacks. They should be made aware that mental health difficulties may be presented in unusual ways or may not be talked about by the person with Asperger syndrome.
20. Health professionals should receive training in assisting people with Asperger syndrome to recognise, and report the symptoms of ill health, and develop appropriate preventative health care strategies for independent living.
21. Primary health counsellors need training in understanding and counselling people with Asperger syndrome. This may include awareness sessions followed up with training in effective counselling techniques for people with Asperger syndrome, for example adapted cognitive behavioural therapy.
22. Greater use of the creative therapies should be made available for adults with Asperger syndrome, in recognition of communication difficulties, and the benefits of drama, art and musical expression.
23. There needs to be consideration of a community based crisis service for people with Asperger syndrome, to avoid admissions to psychiatric units. Some people will only require occasional intensive support, but require a quick response service. Staff in mental health settings, both community and in-patient require training on helping people with Asperger syndrome in emergency situations.

***‘[We spent] many years discussing his difficulties with school doctors, teachers and every professional we came into contact with. When we asked what the problem was we were told, “we don’t label people” ...we were severely disadvantaged with regard to getting correct services. A legacy we are still trying to rectify, even to this day.’***

**(Parent, Avon)**

***‘One psychiatrist noticed it and said he was sure it was Asperger syndrome. Then his boss told me he did not think it was Asperger syndrome! – who were we to believe?’***

**(Parent, North Somerset)**

<sup>28</sup>Avon Asperger Syndrome Project 1999-2002.

<sup>29</sup>The National Initiative on Autism: Screening and Assessment will be producing information on standards in diagnosis later in 2002.

<sup>30</sup>DISCO is the Diagnostic Interview for Social and Communication Disorders, Dr Lorna Wing and Dr Judith Gould, Elliot House. ADI-R is the Autism Diagnostic Interview – Revised, Lord et al, 1994. See bibliography.

## Support pathway for diagnostic assessment

Asperger syndrome is usually defined by two widely recognised, and similar systems (DSM-IV American Psychiatric Association, 1994 and ICD-10, World Health Organisation, 1992).

However, variation in interpretation of the diagnostic criteria is common and professionals often remain confused about how to diagnose adults, or are simply not aware of the condition.

46% (n=458) of individuals with Asperger syndrome were not diagnosed before the age of 16 (Barnard et al, 2001). The average age of diagnosis is about 11 years (Howlin and Moore, 1997).

A GP survey in Bath and North East Somerset found surgeries were only aware of one person with Asperger syndrome over the age of 19 (out of 98000).<sup>28</sup>

### Strategic development for diagnosis

- **Consensus on diagnostic criteria** in the local authority should be established, by Planning Group consultation with key health professionals. This may be part of a wider initiative (for example NIASA)<sup>29</sup>, or decided locally, until any national guidelines are available. Once these are agreed they should be distributed to all relevant health staff including GPs, psychologists and psychiatrists. The NIASA guidance covers young children. Its guiding principles should be implemented across adolescent and adult services as appropriate.
- **Quality standards for assessment and diagnosis** should be established, regionally based on the NHS Clinical Governance framework so that people receive a consistent and sympathetic service.
- **Awareness of Asperger syndrome amongst GPs, psychologists and psychiatrists** needs to be increased. This may be achieved through Continuing Professional Development (CPD) opportunities, with a local expert in autistic spectrum disorders offering awareness sessions. General psychiatrists should have input on their pre-qualifying training on developmental disorders, where mental health difficulties are common, such as Asperger syndrome
- **Diagnostic training strategy** The Planning Group should identify how psychology and psychiatry will reach a uniform and acceptable level of competence in diagnosis. For example – to train two psychiatrists each year for the next three years, using DISCO, or ADI-R<sup>30</sup>. This will cost the health trust money but prevent more costly out-of-area placements in the longer term. The diagnostic training strategy should reach across learning disability and mental health.

## Developing a local support pathway for diagnostic assessment

In children's services there is likely to be a multi-disciplinary team that diagnoses young people with Asperger syndrome. Although this would be useful for many adults, it is probably more realistic for the majority of 'straightforward' late diagnoses to be seen by a single health professional.

In an ideal scenario, every psychiatrist and psychologist within the mental health and learning disability trusts will be able to offer diagnosis of Asperger syndrome. In this situation, if someone asks their GP to be referred for diagnostic assessment, it would simply be a case of locating the nearest appropriate team.

However, a more realistic plan might be for the Planning Group to identify individual psychiatrists and psychologists who have good experience and knowledge of Asperger syndrome to act as referral points for the local authority/health trust area.

This will require at least one or two people with sufficient 'expertise' and willingness to take referrals for adult diagnosis and an acceptance by their line managers that such an ad hoc system is cheaper than out-of-area specialist referrals for diagnosis. The specialist's caseload will need to reflect the small amount of extra work this service may entail.<sup>31</sup>

Such an ad hoc system may be a medium term option until an 'Asperger syndrome assessment and diagnosis' training strategy for psychiatrists/psychologists has been set up.

GPs, psychiatrists and psychologists will need to know who the 'specialists' are in their area in order to refer on.

In some areas there may be a regional Asperger syndrome tertiary service (for example a forensic service) or local learning difficulties health trust autistic spectrum disorder tertiary service which accepts referrals for possible Asperger syndrome diagnosis.

Whichever support pathway to diagnosis is decided upon, there should be the option of a second psychiatrist/psychologist opinion if requested by the person being assessed. There should also be the option of a second GP opinion if the first GP decides not to refer on. If there is no specialist in the health trust, there must be acceptance of the need for out-of-area referrals<sup>32</sup>.

**'We were passed from one professional to another never wanting to give us a diagnosis. We believe this was to spare the parents' feelings and to save money and hide the lack of resources available after diagnosis.'**

**(Parent in Opening the Door report, National Autistic Society, 1999)**

<sup>31</sup>For psychiatrists who have a good basic understanding opportunities to 'shadow' diagnostic interviews by more experienced colleagues may be beneficial and reduce the extra work burden as they develop expertise to diagnosis autonomously.

<sup>32</sup>CLASS in Cambridge currently provide a free specialist adult diagnosis via charitable funding, but most diagnostic centres have to charge for assessment – Appendix B.

## Good practice – a quality diagnostic service

*'I felt we were treated with great respect from the minute we walked through the door ...We were treated with kindness, caring, understanding and we were believed. No one laughed at us or contradicted us. Basically we were treated with an excellent professional approach.'* (Parent)

The Planning Group should establish an agreed quality standard for diagnosis of Asperger syndrome in consultation with practitioners and ensure it is upheld.

A quality service should:

1. Understand that diagnosis ought to be a therapeutic process, not just a 'checklist'.
2. Make a diagnosis, if appropriate, regardless of whether there are statutory services available as a result.
3. Use consensus diagnostic criteria.
4. Make a full diagnostic assessment including developmental history, whenever available.

## ...continued

5. Use a combination of observation, standardised interview and clinical experience.
6. Identify psychological, physical, social, and other needs of the adult, as well as practical suggestions to ameliorate any particular difficulties the individual is facing.
7. Produce a document to state diagnosis, which criteria and tools were used to assess and describe any co-morbid conditions.
8. Be aware of the need to involve both the person with Asperger syndrome and parent/carer if applicable in the assessment and explanations.
9. Give clear, sensitive verbal explanations of the syndrome and provide quality, written information.
10. Refer on for any relevant genetic counselling.
11. Be tailored to individual understanding.
12. Dedicate sufficient time for assessment .
13. Offer people a follow up appointment, preferably face to face, to ask further questions.
14. Offer clear explanations if diagnosis of Asperger syndrome not made (and any differential diagnosis) and offer second opinion, as appropriate.
15. Provide signposting to post-diagnostic and other services, such as support groups and/or The National Autistic Society.

## Identification of undiagnosed adults by other services

- Good quality secondary screening tools must be available to mental health and learning disability services, so they can make necessary enquiries if someone may have Asperger syndrome but is undiagnosed. These sorts of secondary screening tools must be delivered within a training package to avoid misapplication.
- Awareness sessions for staff in non-specialist community settings (Employment Service, Connexions, further education) should give basic information about what to do if they believe someone has Asperger syndrome and is undiagnosed.
- Schools' SENCOs and educational psychology teams should discuss the best approach to use if they suspect a teenager has Asperger syndrome and is not yet diagnosed.
- Diagnostic assessment should be made available for people even if they do not meet eligibility criteria for community care.<sup>33</sup>

<sup>33</sup>For example, a person is referred to the mental health team for 'depression and obsessive behaviour'. An assessment is made which states that the person is not eligible for community care services. However, the person should still be referred to the team psychologist or psychiatrist for assessment regarding possible diagnosis, if appropriate.

# Information for people with Asperger syndrome and their families

Asperger syndrome is still often an ‘invisible’ condition, and families affected by the syndrome find it hard to get good advice and information. It is important for information to be produced that assists those affected by the condition to get the support they require.

1. Production of an information resource<sup>34</sup> should be developed by the Planning Group. This should include information giving brief overviews of topics likely to be of relevance.
2. All those referred to in the information resource must be involved in the preparation so that information is accurate and useful.
3. The resource should be written in clear, unambiguous language so people with Asperger syndrome can use the resource.
4. Information should be made available on the web and in accessible formats for people who are deaf and/or blind.
5. Information should be made available in relevant community languages for the local authority. Efforts must be made to increase support offered to families who are not White British, by disseminating the resource in ethnic areas and backed up by awareness sessions on autistic spectrum disorders.
6. Information should be easy to follow, and if possible, the resource should provide the key ‘point of entry’ for each service that a family or individual may require.
7. The information resource needs to be kept up to date. The Planning Group could have responsibility for setting up a small team to meet once a year to review and amend material as necessary.
8. The National Autistic Society Branches or local societies may already be producing information packs for families, so local authorities should work in close partnership with these important support groups.

***‘I’ve read so much about autism but I find it hard to get the information I actually need. It is all theory, when I need practical advice I can use.’***

**(Parent, Avon)**

<sup>34</sup>Providing information for families about services is a legal duty under the Chronically Sick and Disabled Persons Act 1970, section 1. An information resource AS INFORM has been produced for families in Avon, which may prove a useful template for other areas to use (National Autistic Society, Bristol). The Autism Handbook is an excellent information and advice guide produced by The National Autistic Society.

## Good practice – topics for an information resource

- Getting support in secondary education and during transition
- How to get support in continued education
- Questions to consider before starting a college/ university course
- Employment
- Diagnosis
- How to request community care
- Accommodation
- Counselling
- Independent living
- Support groups
- Leisure time
- Short breaks (respite care)/befriending
- Welfare benefits
- Transport options
- Other voluntary agencies
- Emergency situations
- Legal advice
- Local and national resources

## Crisis intervention

Too many people with Asperger syndrome are ending up on mental health wards, when their needs could be better met by appropriate community resources.

A service is required which can cope with the demands of people who may react to stress in unconventional and sometimes in aggressive ways. The service could be part of an existing mental health facility or separate regional service. It would use approaches that reduce the need for in-patient mental health facilities, by understanding the nature of autistic spectrum disorders under crisis conditions.

A crisis service would be able to save local authorities and health trusts money by using community based active interventions with people experiencing psychological breakdown.

A crisis service should:

- Be responsive to the specific needs of adults with Asperger syndrome under stress, and those with specific mental health difficulties. Understand the need to reduce external 'pressures', reduce choices, provide structure, and avoid confrontation or arguing.
- Have access to respite community-based homes rather than resort to in-patient facilities.
- Be accessible by families as well as people with Asperger syndrome.
- Be able to visit people with Asperger syndrome in their own homes.
- Be able to access emergency placement(s) that understand autistic spectrum disorders, whether residential or family based adult placement.
- Have clear communication routes and understanding with link agencies: mental health services; specialist facilities; police, probation and youth offending teams and local solicitors.
- Ensure that all link organisations have received relevant training.
- Have staff trained to be an 'appropriate adult' (*Police and Criminal Evidence Act, 1984*).
- Work in a pro-active way with police and other agencies. Information about people likely to require an 'out-of-hours' service should be circulated to social services and police before further incidents occur. Details of approaches that will enable behaviour to de-escalate will be necessary.
- Ensure all involved agencies use a consistent approach and information is shared.

## Secondary schools – preparation for adult life

Although these guidelines are aimed at resources for adults, the teenage years are very important to get right. If students can be successfully supported at school, it will equip them with the confidence and skills to make the most of continued education and employment opportunities.

Most pupils with Asperger syndrome do not have a Statement of Special Educational Need (SEN). Therefore service planning and provision needs to take account of this.

One in four pupils with Asperger syndrome experience periods of exclusion from schools (Barnard et al, 2000).

Pupils with Asperger syndrome need specialist approaches, and education must include development of the social aspects of their lives for it to be successful.

### Recommendations for secondary schools

1. Each Local Education Authority (LEA) should collate and make use of data on both Asperger syndrome and other autistic spectrum disorders to facilitate planning.
2. Each LEA should have a clear detailed internal policy on education for pupils with autistic spectrum disorders. This will include policy on home-tutoring, staff training policy, admission to Asperger syndrome/ language units and out of local authority placements.
3. Each LEA should produce written literature for parents on its work with children who have an autistic spectrum disorder. These may give a brief overview of the local authority's policy towards education of pupils with Asperger syndrome, and criteria for educational placement within any units or other specialist provision.
4. Each LEA should employ an outreach service for mainstream schools. Colleagues in specialist units or schools should also assist with training and information.
5. Each LEA should encourage training for staff and make links with local universities/autistic societies to develop accredited staff training modules on Asperger syndrome.
6. Awareness about Asperger syndrome needs to be better addressed in teacher training. Links with teacher training colleges/universities should be in made in order to develop course modules.
7. Each LEA should have senior staff representation on the Planning Group on adults with Asperger syndrome, which will facilitate joint work initiatives with social and health services.
8. Schools should consider the physical environment – floor coverings, lighting, quiet areas, homework rooms and try to make adjustments for students with Asperger syndrome. Having a safe place for students to go to if they feel overwhelmed and require a break from continuous social contact is very important for students with Asperger syndrome.<sup>35</sup>
9. School governors should be made aware of students with autistic spectrum disorders and the resources to meet their needs.

***'I blanked out most of my school days...most of the time I just went off somewhere mentally...'***

**(Jack – person with Asperger syndrome in Sainsbury, 2000 p. 86)**

***'He left school very early because he had a lot of trouble at one stage ...with teachers and other children. His final year at school was the worst he's ever been – he was suicidal.'***

**(Parent, National Autistic Society, 1996)**

<sup>35</sup>Reference Disability Discrimination Act 1995/ SEN and Disability Act 2001.

10. School special educational needs co-ordinators (SENCOs) should ensure they link parents, teachers, and students with outside agencies and support groups as necessary.
11. Awareness training should encourage a consistent 'whole-school' approach. This should be carried out across LEA schools on a rolling programme. Awareness needs to include teachers, learning support, playground and lunchtime supervisors, governors, school nurse/ counsellor and administrative staff. Senior staff should encourage an inclusive ethos.
12. Teachers should be given straightforward practical advice they can actually use in the classroom, when they have many other students to teach. Whilst awareness is important, further job specific training and should allow time to ask about individual students and approaches they can use. Time should be set aside for teachers to discuss students with SENCOs.
13. Each student identified with Asperger syndrome should have clear guidelines in their Individual Education Plan (IEP) to ensure they are able to learn and cope socially. Each teacher of the student should be aware of the IEP. This would include details of how best to manage behaviour, where the child prefers to sit, key words to use/avoid, and which is the nearest "safe room" to use.
14. IEPs should identify exam preparation required for students and any concessions necessary for the person to take the exam, for example extra time, separate room or prompters.
15. Schools should work closely with parents who have a child with Asperger syndrome. Parents should be partners in the education of their child and this is especially so when consistency is important to reducing anxiety for the student. Home-school books, letters, and phone contact may be used as appropriate.
16. Careful thought should be given to the choice and continuity of class teacher, teaching assistant and peers for the pupil who has Asperger syndrome. Students should have a named person they can go to if they get into personal difficulties.
17. Each student with Asperger syndrome should be assessed for social education needs. There may be a need for individual or group work<sup>36</sup> on social education issues – peer relationships, communication, team-work, Social Use of Language Programme (Rinaldi, 1992).
18. Each school should have a specific anti-bullying policy, which has a low tolerance for abusive student behaviour (*Special Educational Needs: Code of Practice*). The school should develop a plan for 'supervising' unstructured time, such as playtime, lunchtime and even journeys to and from school, if necessary, as part of their anti-bullying policy and give students ideas on how to use lunch and break-times.
19. Students without Asperger syndrome should receive social education on autism and attempts to include the person with Asperger syndrome should be made a central part of strategies to prevent bullying and build understanding. A Circle of Friends (Whittaker et al, 1998), or similar initiatives should be used positively to develop relationships, not just to stop the person being bullied.
20. Work placements for pupils with Asperger syndrome should be carefully prepared and realistic. Unrealistic careers direction at 14 can cause great difficulties in adulthood. Work placements should know about the student's learning needs, wherever possible, to avoid misunderstandings.

<sup>36</sup>For example pooling teaching assistant hours to provide groups on social development.

## Transition planning

People with Asperger syndrome are often at their most vulnerable to mental health difficulties when they are insufficiently prepared for change. Therefore the transition from school to continued education and work is very important for agencies to 'get right'. Support from agencies commissioned to help young people must continue after leaving school until the person is settled.

Since most students with Asperger syndrome do not receive a Statement of Special Educational Need (SEN), it requires agencies to find alternative methods of working as well as transition reviews.<sup>37</sup>

### Planning Group on Asperger syndrome – transition representatives

Each local authority should have a Planning Group on Asperger syndrome. The membership should include all professionals relevant to Transition from school to adult life.

- representatives from each local Further Education college learning support (or similar title)
- local university disability officer (or similar title)
- Senior SENCO representative from the local secondary school SENCO network
- Senior educational psychologist
- Connexions Personal Adviser for complex needs in mainstream schools
- Social services representative.

The Transitions Planning Group representatives should map out links between schools and colleges and agree a support pathway for transition. This will involve stating what support each student with Asperger syndrome can expect from them.

### Sample support pathway for transition

During transition it is most important that the student with Asperger syndrome has consistent support and information. Good practice will require a named person to oversee the move from school to college. The following support pathway is an example of how to support students from aged 14 with Asperger syndrome.

1. Each school should identify pupils with Asperger syndrome regardless of whether they have a behaviour problem or Statement of Special Educational Need (SEN).
2. Each year the school SENCO should discuss and pass relevant information to the Connexions Personal Adviser about the social and other support required in the future for students from age 14 who do not have SEN.
3. All students with diagnosis of Asperger syndrome or 'suspected' should be referred by the SENCO to be interviewed by the Connexions Personal Adviser who has more experience of complex needs.
4. The young person and their parents should be a part of the planning process and this may be easier to achieve if any social or academic difficulties have been acknowledged both by school and the family.

***'All children with AS have problems with change. If you combine this with the problems of adolescence, you have the most difficult time so far!'***

(Parent, Berkshire)

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

(Parent, in Barnard et al, 2001)

<sup>37</sup>Avon Asperger Syndrome Project found only about 1 in 5 pupils with Asperger syndrome receive a Statement of Special Educational Needs.

**‘I didn’t have anyone to talk to who understands my condition.’**

**(Person with Asperger syndrome, Bath and North East Somerset)**

**‘He had a bad experience starting at college. Adamant he won’t try again.’**

**(Parent, Avon Branch, National Autistic Society)**

## ...continued

5. The Connexions Personal Adviser should make sure he or she has got all relevant information from the SENCO before interviewing the young person and make efforts to get any further information from parents (preferably before interviewing the young person, but if not, afterwards).
6. The Connexions Personal Adviser may then need to involve other agencies such as health or social services if needs are identified and the person does not have SEN and transition reviews. It may be that Connexions will commission an assessment if it is felt the young person has difficulties that need to be addressed.<sup>38</sup>
7. If the student is leaving school and going on to further education or university the Connexions Personal Adviser should liaise with the necessary agencies possibly including social services, Connexions, further education learning support staff, university student welfare office/disability officer, or similar.
8. The Connexions Personal Adviser will need to spend adequate time with the pupil to explain realistic choices, and prepare him or her to face leaving school, and ensure a smooth transition. The Personal Adviser should be aware that regardless of whether the person appears calm, this is a stressful time for the student. Clear explanations will be required.
9. Ideally, the Connexions Personal Adviser will remain the link person from school to college and into employment or other appropriate setting. There could be a specialist Connexions post who would accept referrals concerning pupils with a diagnosis of Asperger syndrome, with or without SEN. The worker would help agencies produce long term plans.
10. If social services input is required, information needs to be passed to them, so they make their assessment of need (under the Children Act 1989) with the necessary background.
11. Assessment of need (whether at a transition review or by social services under section 17 *Children Act 1989*) for a young person of transition age must be comprehensive – not only pointing out areas of need, but more importantly describing how those needs will be met, by whom, by when, how achievement will be measured and when the plan will be reviewed.
12. At the review before last year of school (or earlier depending on funding for example – if residential college is a likely option) student will visit local colleges (or research opportunities at universities) and be shown around by the learning support manager for each college. Student may require family member and SENCO to go along for support.
13. Students need to be assessed on a number of areas before embarking on further or higher education. This should include social education ability, self-organisation skills, and cognitive skills/learning styles. Also practical matters, such as how the student will get to college, or whether it is better to live at home and go to a local university will need to be addressed.

<sup>38</sup>Section 140 of *Learning and Skills Act 2000* may apply here.

## ...continued

14. Once a place has been decided upon there should also be a clear plan put together of what help is required to meet learning and support needs. It could include personal tutorial, learning support, and counselling time.
15. Connexions (or other responsible agency) should ensure they oversee the process of application and starting in continued education. This person will assist with transfer of information to college/ university, such as explaining learning style, helping the family apply for financial student allowances, and making sure the person gets settled before 'handing over' to a contact within the continued education setting.
16. Students with SEN will find it easier to get extra learning support. If there are other students without SEN, the college learning support department should get a letter from the person's GP or the consultant who diagnosed, stating the need for extra help in or out of lessons, as appropriate.
17. Schools should make school reviews, IEPs, SEN and other relevant information accessible to college/university.
18. Further education learning support staff should be pro-active and go into schools to see students who may require support. This will allow them to discuss teaching needs and should aim to reduce anxiety for the student.
19. Further education colleges should produce information on 'support for students with an autistic spectrum disorder' to give out to schools and families. This will include information on providing transport.
20. Colleges and universities should have separate wording about autistic spectrum disorders and their approach within their disability policy.
21. Enrolment forms should ask explicitly if the student has a disability (diagnosed or not) and also whether the student will require any social or learning support whilst at college/university.

## Assessment of young people at transition (under Education Act 1996, or Children Act 1989)

This is a suggested outline of areas to consider in assessment, not an exhaustive list of needs. It is based upon the *Framework for Assessment of Children in Need and their Families* (Department of Health, 2000, p.19).

Few young people with Asperger syndrome receive a Statement of Special Educational Needs (SEN) so if they require social support on leaving school their parents may request social services assessment of need under section 17 of *The Children Act 1989*<sup>39</sup>.

Whether the person's needs are being considered in a transition review, or under *The Children Act 1989*, the following headings may be of use.

**Health needs** include exercise; diet; self-managing any physical difficulties or medication; understanding of sexual health.

The action plan might include the need to understand personal care; getting enough sleep; how to relax; how to manage any additional physical difficulties (for example epilepsy, obsessive compulsive disorder, attention deficit/hyperactivity disorder).

**Education needs** include receiving adequate education; experiencing success; the opportunity to develop understanding through peer interaction; learning styles; the ability to problem solve and cope with educational environments; an awareness of own skills and educational abilities; a degree of realism about possible future vocations.

The action plan might include the need for social education (learning about relationships and communication); the need to learn anti-bullying tactics; extra time to think through vocational choices.

**Emotional and behavioural development needs** include looking at the quality of peer relationships; appropriateness of response to others; behavioural difficulties; stress and anxiety measures; any mental health issues.

The action plan might include the need to control anger towards self and others; the need for assistance with depression, obsessions, panic attacks, agoraphobia,

social 'exposure' anxiety, paranoia; the need to reduce social isolation; help in leaving the house/bedroom.

**Identity needs** include sense of self as a separate and valued person; quality of self-image; feelings of acceptance; degree of community integration; quality of social identity; awareness of disability.

The action plan might include the need to talk about and meet others with Asperger syndrome in an understanding environment; the need to discuss what is Asperger syndrome and what is 'me'; the need of a befriender to go to a local club.

**Family and social relationships needs** include quality of social interaction; ability to interact successfully with peers and develop intimate relationships.

The action plan might include the need to improve the ability to relate to others (possibly including social skills); the need to develop appropriate relationships/sexual behaviour; the need to control anger towards parents; parents' needs for short breaks; siblings' needs to understand behaviour and have breaks from caring role.

**Social presentation needs** include the growing understanding by the young person of how he or she is perceived by others; his or her ability to adapt social role as necessary and to preserve self-esteem.

The action plan might include being able to explain Asperger syndrome to others (acquaintances, college students, employers); someone to talk to about self presentation.

**Self care skills needs** include the acquisition of practical, emotional and communication skills to increase independence, opportunities to engage in activities away from the family, having social problem solving skills.

The action plan for self care skills might include:

- the ability to travel independently
- the ability to use public transport safely
- having someone to talk to outside the family (for example befriender, clubs)
- the need to plan for living independently of his parent/carers (housing options)

## ...continued

- the need to understand personal safety outside the home
- how to recognise and avoid 'risk' situations
- the need to learn how to look after himself
- personal care and grooming
- the need to develop practical life skills – cooking; laundry; cleaning
- the need to develop financial independence/ability to manage own money.

***The transition plan should aim to give precise details of how any needs identified will be met. It is not just a description of someone's difficulties but a list of actions to be carried out in order to address those difficulties.***

<sup>39</sup>Connexions Personal Advisers may also decide the young person requires support under the *Learning and Skills Act 2000* section 140. This allows for an assessment of need to take place before the person leaves school, and could cover social support needs.

## College or university

***‘The best support would perhaps have been to know about other Asperger syndrome people at the university to form friendships whether in the course or in the university as a whole, and maybe to have had staff who would appreciate some of the problems.’***

**(Student with Asperger syndrome)**

***‘(I require) support when needed in lectures ...quiet room to go and study in ...help with changes and new routine ...better teaching methods.’***

**(Student with Asperger syndrome)**

People with Asperger syndrome usually have average, or higher intelligence and can greatly benefit from college or university education.

Unfortunately, many experience difficulties accessing tertiary education, for a mixture of reasons. Many students become isolated, lonely and find their social difficulties increase, without necessary support. Students also often struggle because the academic approach demanded by colleges/universities is not differentiated to their learning style.

### Support pathway into college or university

The Planning Group representatives for colleges and local universities should work with their colleagues in those institutions to develop good practice for people with Asperger syndrome wishing to study.

As stated in the section on transition, the student should have the support of Connexions or other professionals in order to make the move into college or university. Students will often require advice about applying for support and asking the right questions before choosing a course.

The following are some of the important areas to consider and for the Planning Group to encourage across all local colleges and universities.

1. Awareness sessions on Asperger syndrome to be taken up by college/university, for all staff - ‘Systems approach’ (reception, tutors, learning support, student counsellors, restaurant/canteen staff).
2. Learning support, counsellors and disability officers will benefit from ‘job specific’ training on Asperger syndrome to enable them to provide effective pastoral support.
3. First impressions are important to people with Asperger syndrome. A coherent protocol for students entry into college/university, should be established including:
  - enrolment forms with mention of developmental difficulties such as Asperger syndrome
  - stress reducing ‘welcomes’ (for example prior contact with an understanding personal tutor, home visit)
  - ensuring funding is in place for any learning support before term starts
  - good induction and orientation (for example providing maps of the campus, and important contacts)
  - a flexible approach (for example allowing visits during holidays for familiarisation)
  - establishing positive contact with parents, when appropriate.
4. Colleges locally should discuss good practice and share ideas, about how best to support students.
5. Colleges should consider Asperger syndrome specific courses, ‘open-learning’ or outreach courses to assist those who find traditional provision prevents them from learning.
6. Colleges should consider courses which help prepare people for work, by developing closer links with employers, and which address the specific employment needs of people with Asperger syndrome (National Autistic Society, Prospects Supported Employment Consultancy).

7. Some colleges in the UK offer Asperger syndrome specific post-school options. These institutions could be contacted for ideas on good practice<sup>40</sup>.
8. Link courses can be considered for students to test out local colleges/ universities facilities and whether the course content suits from 14 onwards.
9. People with Asperger syndrome and their families should have access to a checklist of questions to ask any proposed college or university.
10. A good practice guide is needed for colleges and universities when including students with Asperger syndrome. This guide could be part of a training package and might include elements such as:
  - an explanation of Asperger syndrome
  - how the condition affects an individual's ability to learn
  - a preparation checklist before the student starts the course
  - a social needs checklist
  - an academic/learning needs checklist
  - an exit strategy checklist
  - useful contacts within college and links to specialist agencies.
11. There should be differentiation of teaching and different formats for taught material. Students should have access to taping equipment for lectures and photocopying should be made available, using student allowances.
12. Assessment of support during exams should be made available, such as extra time, someone to scribe, prompts, or a distraction free room.
13. Adequate support structures should be identified by the college/university. These could include disability groups or Asperger syndrome specific groups, or 'befriender' schemes.
14. The students' union or welfare officer should provide a knowledgeable service to all new students with Asperger syndrome identified on enrolment, and provide ongoing pastoral support throughout the person's education.
15. Each institution should be able to identify someone with a good understanding of Asperger syndrome to provide advice and support to tutors (Portway, 2000).
16. The college or university campus should identify quiet rooms for people with Asperger syndrome to relax, and use as their own area.
17. A coherent protocol for students' exit from college/university needs to be established. Each student must leave college or university with a clear, realistic plan. Ideally there would be reviews in the final year so that any difficulties for transition to work, or other pursuit can be assessed and discussed. Connexions should become involved again if people with a disability are under 25 and require guidance.

***'I try to talk to other students, but they just give me a funny look, or they just don't answer.'***

**(Student with Asperger syndrome)**

<sup>40</sup>For example, Nautical College, Glasgow; Interact College, London; ESPA, Sunderland; Farleigh Education Group, Somerset . See Appendix B for contact details.

***‘Diagnosis is a very lonely process. It can leave you in a state of despair, shock and bewilderment. There is no one on the diagnostic side to direct you after you have received a diagnosis. What happens now? Where do we go for help and advice?’***

**(Parent, South Staffordshire)**

***‘My son has only just been diagnosed and I am still coming to terms with it...For me, as much information on the subject as possible helps and to be able to talk to others in a similar situation really helps when I’m feeling so isolated and alone.’***

**(Parent, Berkshire)**

***45% of parents state that the disability was explained inadequately or not at all.***

**(Stirling and Prior, 1999)**

## Post-diagnostic support

Previous local authority audits of need and national survey reports have consistently highlighted the stress on families and adults with Asperger syndrome seeking diagnosis.

As well as poor diagnostic services many families do not receive any post-diagnostic follow up.

### Post-diagnostic support for parents/carers

For parents and other carers there seem to be three distinct needs relating to diagnosis.

1. Good diagnostic assessment, including explanation and follow up (see support pathway for diagnostic assessment).
2. Post-diagnosis support, in the months after diagnosis
3. Ongoing support.

Parents and carers need to receive timely and good quality information on Asperger syndrome, during the diagnostic assessment process itself and clinical follow up, but also in the months after diagnosis.

Whilst the emphasis is providing awareness and training for professionals, it is easy to forget that it is usually parents who provide most of the support to those with Asperger syndrome. It is therefore important to offer quality educational information and advice to parents so they are equipped to offer the best support they can.

The Planning Group should consider commissioning post-diagnosis groups for parents during the first 6-12 months after diagnosis. They should run for about 6-8 weeks and cover the following:

- a brief explanation of Asperger syndrome
- how best to understand and support their son or daughter
- how to understand and respond to difficult behaviour
- support for siblings
- how to develop their son’s or daughter’s independence skills
- what support is necessary in college/university/employment
- how best to discuss the diagnosis with other people
- how best to approach the difficult subject of their son or daughter moving into their own accommodation
- relevant legislation, welfare benefits and rights
- community care assessment
- making future provision – trust funds, wills
- links – who to contact for support in the locality, sources of information.

The National Autistic Society has developed a support programme called *help!*, which addresses many of the above topics.

## Good practice – post-diagnostic education and support for parents (help! programme, The National Autistic Society)

The National Autistic Society developed the *help!* programme in response to the needs of parents who felt ill-equipped following diagnosis to best support their son or daughter and themselves. It was discovered that in most places in the country post-diagnostic support is under-developed and parents are not getting the information, advice, support they require.

*help!* is an acronym for Help, Education, Listening ears and Positive strategies and it is a programme that works alongside small groups of parents, over 6-8 weeks to enable them to 'orientate' themselves to the diagnosis and the future.

The programme provides information on autistic spectrum disorders and how they may affect an individual's future, on educational approaches for support, behaviour management, welfare benefits and a number of other topics.

So far the programme has been a real success and benefited parents in emotional and practical terms.

One father, whose son was living away because of behaviour difficulties, told the group that he was having his son back

home, on a gradual basis, as he had learnt so much from the *help!* programme and developed confidence to meet his son's needs.

A set of parents whose daughter is very withdrawn, has learnt from the behaviour module that giving the person space is sometimes a better tactic than trying to constantly encourage and invite her to 'join in'. By reducing pressure, the daughter is starting to drift into the family's activities and show more interest than previously.

There may be scope to look at similar post-diagnosis programmes for people with Asperger syndrome in the future.

*Post diagnostic groups such as those in the help! programme would seem to be a cost effective approach to assisting families. They can give parents confidence by providing information within a mutually supportive atmosphere. They learn about approaches, ways to manage challenging behaviour, welfare benefits, education, their rights and so are likely to reduce the need for professional intervention.*

## Post-diagnostic support for adults with Asperger syndrome

Adults recently diagnosed with Asperger syndrome require post-diagnostic counselling support over several months. Although diagnosis usually seems to bring a sense of relief, for those old enough to understand what it means, there will be a number of reactions to having Asperger syndrome on a day to day basis.

One thing that can assist most people to adjust and 'come to terms' with diagnosis is information and the opportunity to talk. The exception to this may be people who are diagnosed but denied having any difficulties before. These people may not wish to discuss Asperger syndrome at all following diagnosis.

For adults who were not diagnosed until their teenage years, or later, there can be anger about how much time has been 'wasted', how badly they were treated at school, and about professionals who misdiagnosed them. People may also perceive the diagnosis as the end of being able to aspire to 'normal' lifestyles and this may take time to consider and come to terms with.

Therefore post-diagnostic support is an important part of the therapeutic process and should not be rushed.

***'I feel like the sun has started shining after the rain...I can make sense of why I am like I am.'***

**(Person with Asperger syndrome)**

***In the majority of cases, people with Asperger syndrome feel getting a diagnosis is the start towards positive change.***

**(Gresley, 2000)**

Since Asperger syndrome is a ‘medical’ diagnosis, health professionals should see post-diagnosis as an important feature of their work. Giving someone a ‘label’ without proper explanation or ‘treatment plan’ is not helpful.

Individually or in a group, post-diagnostic support should include discussion and information on the following elements:

- diagnosis explained again in more detail
- possible emotional reactions
- examining past events in light of new diagnosis
- disability awareness: strengths and abilities
- disability awareness: differences and challenges
- disability awareness: what is me and what is Asperger syndrome?
- being in control; self advocacy; being positive
- how to explain Asperger syndrome to people outside the family
- implications for family members and friends
- facing the future; independent living options
- welfare benefits and services – how to request support
- ensuring the person is linked into information dissemination, with professionals and services
- opportunities to meet others with Asperger syndrome and attend ongoing support groups.

The overall aim is to give people a better self-understanding and positive view of diagnosis. It may also be about identifying needs and securing any necessary ongoing support.

## Carers' needs

The majority of adults with Asperger syndrome live at home with their parents who are often the sole carers for their sons or daughters, providing regular and substantial amounts of care and support (National Autistic Society, Barnard et al, 2001). It is important that local authorities accept their responsibility to assess the needs of parent carers.

When carrying out assessment of need under *The NHS and Community Care Act 1990*, care managers should have regard for the carer's needs under *The Carers Act 1995*. Checklist (guidance for assessment):

*'The carer's perception of the situation, tasks undertaken, social contacts and other commitments, emotional, mental and physical health, impact on sleep patterns, information about breaks from caring, support required...'* (Social Services Inspectorate 1995a, p.12)

Care managers need to understand how to broach the subject of independent living and the future when they are working with families who have an adult son or daughter, still living at home. This requires skill and sensitivity.

When someone with Asperger syndrome declines an assessment of need, the care manager should look to meet the needs of the carer, including health needs, via necessary support services:

*'There should be a right for the carer to be able to sit down with the social worker and explain their position''* (House of Commons Debate, Hansard 21/4/1995, col.431).

*The Carers and Disabled Children Act 2000* directs local authorities to assess the needs of carers regardless of whether the carer's son or daughter refuses to be assessed.

Some of the extra tasks that parents of adult sons or daughters regularly have to assist with can include:

- assisting with cooking meals
- providing money advice and management
- helping him or her to relax or calm down
- prompting to attend health services – dentist, optician, chiropodist
- teaching to use domestic appliances
- collecting welfare benefits, reminders to 'sign on'
- shopping for food, or clothes
- prompting to keep kitchen hygienic
- checking his or her presentation before leaving the house
- providing a 'taxi service'
- being his or her companion on outings in lieu of same age friends
- explaining other people's behaviour to him or her
- providing reassurance about paranoid thoughts and irrational fears
- offering emotional support
- having to explain his or her behaviour to others to avoid misunderstandings.

The stresses of being a parent and carer are not usually resented but they do take their toll and affect a number of areas.

**'We don't want him to feel unwanted, but we are both utterly exhausted being his only source of help.'**

(Parent, Avon Branch, National Autistic Society)

**'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?'**

(Parent, in Barnard et al, 2001)

**81% of carers claimed they suffered from stress as a result of caring for someone with an autistic spectrum disorder.**

(National Autistic Society, 1996)

The *Carers and Disabled Children Act 2000* guidance directs local authorities to consider the effect of caring for someone with Asperger syndrome on: sleep patterns, health, time to self, relationships with friends outside the home, any other children in the family, ability to work.

## Services for parents/carers

1. Services should be open-minded when deciding how to assist parents of someone with Asperger syndrome living at home. A flexible response is essential.
2. Post diagnostic services for carers must be provided. These could be groups or individual. There may be access to local schemes such as *help!* (National Autistic Society<sup>41</sup>), which is aimed at parents after diagnosis to equip them for the future. Post diagnostic services need to be aware that diagnosis in one family member may throw up questions for other family members about their own behaviour, related difficulties and possible diagnosis.
3. Carers should be offered ongoing education and support to understand their son or daughter better, and have access to discuss any difficult behaviour with professionals. Many parents are not given sufficient information about the diagnosis, and arguments over behaviour can occur at home, because one parent 'blames the Asperger syndrome' and the other 'blames the person'.
4. Genetic counselling needs to be made available; professionals need to be sensitive to the issues.
5. Many adults will not accept the need for respite type services as such, but may accept a more relaxed 'befriender' type service. Indeed 'befriending' is the most common requested 'respite' service by carers for their adult sons and daughters.
6. If an overnight service is required the placement will need to be made 'accessible'. This will require the placement provider to have received training in Asperger syndrome and be able to offer something that appeals to the person concerned.
7. People with Asperger syndrome who do receive respite with a family as a child may prefer to keep the contact with the family as an adult. This may be achieved by social services allowing the respite family to become an adult placement.
8. It needs to be borne in mind that many adults with Asperger syndrome may not wish to share a respite placement with someone who has very different needs.
9. 'Sitting' services should be available so parents can go out for an evening.
10. Domiciliary care should be available to reduce the stress of caring for an adult son or daughter.
11. The carers' assessment may highlight the need for the adult to receive more assistance with independent living or emotional support.
12. Carers should receive information on welfare benefits.
13. Formal links between parent support groups (such as local Branches of the National Autistic Society, or local autistic societies) and local authorities need to be established. Carers can be a source of expertise on 'what works' in terms of provision and should be consulted on service development.

<sup>41</sup>*help!* details in Appendix B. Carers' needs can be met by counselling and training for which local authorities can pay under Section 2 of the *Carers' and Disabled Children Act 2000*.

## Employment support services

Research shows few people with Asperger syndrome find suitable employment unless they receive specialist support (for example, The National Autistic Society supported employment consultancy – Prospects). Whilst employment is not an option for all, many more people could and would be able to work if they received better support (Barnard et al, 2001).

The Planning Group should ensure that a comprehensive audit of need is carried out. This will involve all services connected with employment opportunities, identifying ways to reduce the high unemployment amongst adults with Asperger syndrome.<sup>42</sup>

Following the audit results, a training strategy should be drawn up for each service. This will involve setting up joint awareness sessions on Asperger syndrome and then arrange job-specific training. Awareness sessions should be multi-disciplinary to encourage joint working.

### Job specific training on employment and people with Asperger syndrome

Job specific training for staff involved in employment, including Connexions and the Employment Service, may lead to the development of an information resource that all professionals can use when working alongside people with Asperger syndrome. It should include the following:

- an explanation of Asperger syndrome
- an overview of employment and Asperger syndrome
- what sorts of jobs people with Asperger syndrome are typically good at
- how to engage and interview people
- helping people to develop a better understanding of their strengths and weaknesses
- how to recognise job readiness
- where to refer if someone is not job ready – links to other agencies
- how to develop a skills profile for the individual
- how to develop the person's interviewing skills
- how to engage with employers to 'sell' the individual – promoting the work skills of people with Asperger syndrome
- obtaining detailed feedback from employers after interviews and from work experience placements
- matching the job situation to an individual's needs (part or full-time, voluntary or paid work, open or supported)
- how to measure job skills
- common difficulties people face in the workplace and how to overcome these
- using models of support in the workplace (National Autistic Society, Prospects)
- how best to use various government schemes to assist people into jobs
- a discussion on whether to disclose the diagnosis and if so at what stage of job hunting to disclose
- *The Disability Discrimination Act 1995* and Asperger syndrome
- information on local employers who are 'Positive about Disability' and/or members of the Employers' Forum on Disability
- sources of specialist advice and information.

***'People with Asperger syndrome can make a positive contribution, particularly in the workplace if their disability is properly understood and they are helped in a positive way.'***

**(Person with Asperger syndrome, West Midlands)**

***'He is in and out of work. Quite frequently he is capable of a wide range of jobs but usually comes unstuck due to communication problems.'***

**(Parent)**

<sup>42</sup>Avon Asperger Syndrome Project 1999-2002 found unemployment rate of approximately 65% (n=52).

***'I have had six different Disability Employment Advisers: none of them has helped me get a job.'***

***(Person with Asperger syndrome)***

## **Other employment issues**

1. The employment information resource should have a section that can be photocopied to give to potential employers. For example, a section on 'why people with Asperger syndrome make good employees' or 'small adjustments to make in the workplace to get the most out of your employee with Asperger syndrome'.
2. There should be a separate information resource for people with Asperger syndrome on employment. It will include 'jobs people with Asperger syndrome are often good at'; 'whether to tell an employer about Asperger syndrome'; 'what sort of job will I be best at?' and 'am I ready to start work?' Such self-assessment material may help some people focus on realistic job choices.
3. People with Asperger syndrome may come into contact with over 10 different professionals or services relating to employment opportunities. There is often conflicting advice and lack of co-ordination.
4. Part of the audit should try to identify a clearer support pathway and clarify the role of the Disability Employment Adviser. Disability Employment Advisers require a much better understanding of people with Asperger syndrome if they are to enable people to get appropriate jobs.
5. Ideally, a specialist employment scheme should be set up on a local authority or regional basis, to support people with Asperger syndrome into work.

***'Failure to transfer the skills acquired through education to the workplace is a clear waste of resources. Continuing and unnecessary reliance on state benefits is also extremely expensive, as are the costs of treating psychiatric disorders relating to long term unemployment.'***

***(Mawhood and Howlin, 1997)***

## Benefits

People with Asperger syndrome often struggle to get adequate support from the Benefits system. Most people are often judged 'too able' to get any disability benefits but not able enough to be offered any work. This 'catch 22' situation can have a profound impact on a person's self confidence and ability to live independently.

There are several areas where people with Asperger syndrome receive poor service, including the following.

- The low and middle rate Disability Living Allowance care component is often refused for people with Asperger Syndrome despite substantial amounts of care and support being provided by parents and others. This is often due to a lack of understanding by Department of Work and Pensions staff in disability benefit centres.
- The work test for Incapacity Benefit is often applied inappropriately by Department of Work and Pensions staff, so people who are unable to work, for example due to social anxiety, are deemed ineligible to receive financial help.
- Visits to the jobcentre for those claiming Job Seekers Allowance are often stressful: staff put undue pressure on many people with Asperger syndrome due to a lack of understanding of the condition.
- The system whereby a claimant loses benefit if he leaves a job 'voluntarily' works against those with Asperger syndrome who are sometimes incited, or feel coerced to leave jobs, because of teasing and bullying.

### Benefits service recommendations

The Planning Group should develop understanding, possibly using disability rights organisations to set up job specific training.

1. Department of Work and Pensions staff in jobcentres should receive training in the needs of people with Asperger syndrome, so that the process of 'signing on' is made more tolerable.
2. Department of Work and Pensions staff in disability benefit offices should receive training in autistic spectrum disorders so they can properly assess the eligibility of people with Asperger syndrome to disability benefits.
3. Social and health care services should support people with Asperger syndrome in their dealings with Department of Work and Pensions staff.
4. Social and health care services need to support people making applications for disability benefits (including carers' allowances). A thorough understanding of the information requirements of the disability agencies within the Department of Work and Pensions is essential. Forms must be filled out correctly, representing the individual's needs.

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

**(Parent, Barnard et al, 2001)**

***‘It is not that we resent him still being here, but there again we can’t let him go until there is somewhere he can go. He cannot cope on his own and there is no help, so he ends up back here again.’***

**(Parent, Somerset)**

## Accommodation services

Most adults with Asperger syndrome live with parents because there is no support to help them develop independence. Not only does this cause a lot of stress, it goes against the ethos of *Valuing People* – which enshrines the principle of offering people a choice about where they live (Simons, 2001).

There is a great need for independent accommodation. As parents get older, they are often less able to provide support, and would like to be able to enable their son or daughter to live away.

A range of housing options is necessary. Some people with Asperger syndrome choose to live alone and would find it hard to tolerate anyone else’s company. Others will want daily contact, but self-contained accommodation (so cluster flats may be appropriate). Others may wish for a little less contact and choose to live in a community scheme. Occasionally people with Asperger syndrome will require residential care.

The Planning Group will include representatives from local housing associations, local authority social services, Supporting People officers and agencies that offer support workers.

Following the audit of housing service need, the Planning Group representatives should encourage the local authority, in collaboration with relevant agencies and specialist advisory groups such as the National Development Team or The National Autistic Society, to incorporate the varied needs of people with Asperger syndrome into their planning processes.

## Guidelines for accommodation

The following three aspects of housing provision lead towards successful accommodation for people with Asperger syndrome.

### ■ Consideration of options

Sensitive and pro-active support to people with Asperger syndrome and their families which helps them consider the housing and support options available and to decide upon the best way forward for them.

### ■ Flexible housing options

A range of options that meet the varied needs of people with Asperger syndrome.

### ■ Flexible support options

A range of support methods which are individually tailored, through the person centred planning approach, to meet the specific needs of each individual with Asperger syndrome. This will include trained staff to provide ongoing support as necessary.

## Consideration of options

1. Many people with Asperger syndrome remain living with their parents and are quite anxious about any thought of moving out. Social services and housing providers should be aware of the care required when discussing the subject of living more independently.
2. There will be training implications for staff discussing independent living options. A specialist housing provider for people with Asperger syndrome may be able to offer training.

3. The need for family contact is often quite strong, so local supported housing options should be made available.
4. People who have not lived away from their parents before may well require a high level of support initially.
5. If someone is unsure about living away, then a 'trial' 6 months may be a useful way to get the person started towards independence. Many people with Asperger syndrome have quite low self esteem, so steps should be taken to ensure most difficulties are viewed as part of the 'trial' period, not failure.
6. Families become used to making the necessary adjustments to daily living routines, to accommodate their sons or daughters' social behaviour, so it is easy to underestimate the level of matching for compatibility necessary for successful communal living.
7. Before someone decides to move out of the parental home they should complete a personal financial check. With support people with Asperger syndrome are often able to be competitively employed and earn reasonable salaries, and this may affect their entitlement to local authority funded support.

***'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 is taking her medication.'***

**(Parent, in Barnard et al, 2001)**

## Flexible housing options

1. Supported housing under the 'Supporting People' programme (Inter-Departmental Review of Funding for Supported Accommodation 1998) appears to be an ideal opportunity for people with Asperger syndrome to move into independent living without having to meet the eligibility criteria for social worker support. It remains to be seen how this policy and funding framework is used by local authorities.<sup>43</sup>
2. Some people are able to buy their own homes either with help from parents or via shared ownership through specialist housing associations.
3. Other people prefer to live in rented self-contained cluster flats where support is provided on a daily basis to help with independent living tasks. Most people can live in self-contained settings either with other people who have support needs or in dispersed supported living schemes.
4. Some adults require a higher level of daily support, and this will need to include specialist residential houses, with 24-hour staff support, waking night staff and active community programmes.
5. Planners should be aware that provision for people with Asperger syndrome will require a greater number of individual accommodation properties, because of the social difficulties encountered in communal living.
6. Generally self-contained accommodation will be preferred.
7. People with Asperger syndrome may not fit into residential or supported housing accommodation that is primarily for people with learning difficulties or mental health problems. However, each situation will need individual consideration. Some will only wish to live in accommodation with people with Asperger syndrome, others will not. The key is to match tenant compatibility, interests, proximity to family, lifestyle, wishes and feelings. In other words, good person centred planning.

<sup>43</sup>An Asperger syndrome specific service has been created by The National Autistic Society Burnham Service, in partnership with parents and Golden Lane Housing Association using Transitional Housing Benefit general counselling and support funding.

8. The location of appropriate housing is important. Housing should be in 'safe' areas and community risk assessments should be applied. People with Asperger syndrome seem to be quite vulnerable to physical assaults.
9. A sensory audit of accommodation will be necessary, as people with Asperger syndrome may have hyper or hypo-sensitivity to sensory stimuli. Lighting, colour schemes, quiet floor coverings and background noise levels will all need to be considered as well as any other individual sensitivities.
10. Models where a service provider has a tiered support system work well. For example, National Autistic Society Hyndburn service offers residential care, group home and individual tenancies in close proximity to allow people to develop independence in convenient steps.
11. A few people will require specialist or secure accommodation. This may be the case for people who pose a risk to self or others. The National Autistic Society Hayes Unit in Bristol is one such service.

## Good practice – a supported housing scheme (Hyndburn service, The National Autistic Society)

The National Autistic Society set up the Hyndburn service in 1994. It began as a 6-bedded unit – Clayton Brook House. The needs of the people who lived there were varied but included those with 'challenging behaviour'. In seven years the service has expanded to meet the needs of approximately 34 people with autistic spectrum disorders, including many with Asperger syndrome.

The service has successfully supported people to develop independence at a rate that is manageable for each individual. One of the keys to success is having an understanding of the long-term needs of people with autistic spectrum disorders. They require consistency, predictability and structure. This does not mean that life is without challenge or interest, but rather that change is managed in small positive steps to build confidence and achievement.

A lesson for purchasers is that people with Asperger syndrome often thrive in supported environments, and they do so because they are helped by structure and support. People do become more independent, but change must be introduced gradually and without altering all elements of a person's lifestyle at once.

By retaining the same consistent staff approach, being able to access the same day and community services, as appropriate, and by staying within proximity of all that is familiar, the service has successfully helped individuals move from a residential care home setting to having their own tenancy and self contained flat.

In Great Harwood, The National Autistic Society is the registered social landlord for a block of flats that are individually tenanted by people, some of whom previously were considered to require residential care. One flat is retained as a communal social area, people can use as they wish.

A range of housing provision is available all within reasonable travelling distance, so people can move gradually towards independence. For example, someone could move from residential care to a shared tenancy home for six people, or a shared 3-bedroom semi for two people, to an individual tenancy with minimal support.

*Local authority purchasers have seen their costs drop as people with high support needs have moved towards supported housing rather than residential care.*

## Flexible support options

1. Support needs should be assessed and met through the person centred planning process.
2. An assessment of skills is necessary to locate what the person can do already and what support will be required to develop new skills. Support may include both practical and relationship life skills.
3. Support may range from one hour a week advice, to full-time care<sup>44</sup>.
4. Support needs must be assessed carefully by observation as well as interview.
5. Support may be required even for the 'able'. Asperger syndrome produces a very varied profile of skills and weaknesses and types of knowledge. It can mean that people with university degrees may still require floating support. Someone may know how to look after himself but not actually do it, as knowing facts about independent living and being able to live independently are two distinct things for someone with an autistic spectrum disorder.
6. People with Asperger syndrome will often require active intervention from support staff, to encourage acceptable social contact. Staff should be aware of those people who find it hard to motivate themselves, or undertake their own personal care without prompting. Others will just need transport and support to access and take part in social events.
7. These who have support will require regular visits to ensure everything is running smoothly and they are coping adequately. For some people it will not be enough to accept at face value that everything is all right. It will be necessary sometimes to check on hygiene, that bills are being paid, that bedrooms are fit to live in and that the person has got food in the cupboard. Whilst in one sense this is an invasion of privacy, it is also a duty of care for staff working with many people who have autistic spectrum disorders.
8. As well as practical support, people will sometimes require a time each week to talk through their stresses and anxieties. Opportunity to offer effective emotional support should be timetabled into the weekly support package.
9. People with Asperger syndrome will often require support to resolve and 'smooth' neighbour disputes due to their communication difficulties.
10. Support for people who exhibit bizarre behaviour requires careful planning. This will ensure adequate support for them outside their home and prevent their exploitation.
11. Staff may need to spend time preparing other tenants or neighbours about the person with Asperger syndrome. Ideally, this will be with consent, in order to help others understand the basics of communication and the person's social needs. Similarly, the person with Asperger syndrome may require information about other tenants to reduce anxiety and give him or her pointers for social contact.

<sup>44</sup>Models include Birmingham Support Scheme (West Midlands Autistic Society), Northants, Hyndburn, Surrey, Burnham services (National Autistic Society), Wessex Autistic Society, Wirral Autistic Society, but there are many more.

12. Where people with Asperger syndrome live in residential care settings, staff must be taught the skills of active support, to ensure quality in service provision. (*Moving into the Mainstream*, Department of Health, 1998). However, staff also need to know when to give the person space and time away from other people. Training will need to explain difficult behaviour as communication and expressions of anxiety, rather than as deliberate attempts to upset or anger staff.
13. An information folder of emergency numbers and 'what to do if...' advice may be helpful for some people to provide reassurance.

## Partners and families

People with Asperger syndrome may form close adult relationships, and needs arise from these relationships (Slater-Walker, 2002). The person with Asperger syndrome will have a need for understanding and support, as will the partner.

These partners sometimes become 'executive secretaries'<sup>45</sup>: their role becomes full time carer, as well as partner or spouse. The emotional cost of this role should not be underestimated (Aston, 2001).

The Planning Group should work with the local authority, health trust and support groups to:

1. Develop appropriate support services for adults with Asperger syndrome and their partners, in consultation with voluntary agencies such as The National Autistic Society and Relate.<sup>46</sup>
2. Ensure sources of support and information are made available for families who require them.
3. Ensure professionals are made aware during training of the difficulties partners may face.
4. Recognise some partners are also carers, eligible for an assessment of need with regard to their role (*Carers Act 1995, Carers and Disabled Children Act 2000*). However, this is a complex issue that requires sensitive handling.
5. Ensure social services staff receive adequate training in child welfare issues relating to parents who have Asperger syndrome.

<sup>45</sup>A term psychologist Tony Attwood has used to describe the numerous roles a partner of someone with Asperger syndrome may take on.

<sup>46</sup>[www.faaas.org/information.html](http://www.faaas.org/information.html) is a useful website.

## Criminal justice

There is no evidence of a higher rate of offending amongst people with Asperger syndrome (Howlin, 1997). However, the social difficulties of people may make them both vulnerable to becoming victims of crime and on occasion perpetrators (often, though not always, due to relative lack of social understanding). Their inability to understand the potential consequences of their actions may also lead to problems.

The Planning Group should:

1. Work with local police, youth offending teams, appropriate adults, magistrates and other professionals in the criminal justice system to offer awareness sessions and further training on Asperger syndrome.
2. Research local solicitors who offer skills in work with disabled people and offer information on Asperger syndrome for reference. Details of 'autism friendly' solicitors should be included in information resources produced by the Planning Group.
3. Work with local prisons – offer awareness and further training as necessary, for example 'release plans – risk assessment'.
4. Encourage awareness of the work being done in special hospitals, to identify and better meet the needs of people with Asperger syndrome (Hare et al, 2000).
5. Encourage research into local prison populations of people with Asperger syndrome.

# Conclusion

## Responsibility for community care assessment

These good practice guidelines give services an opportunity to better provide for people with Asperger syndrome. However, guidelines will be of little use unless senior management decides who is to take responsibility for community care of adults with Asperger syndrome.

This long neglected decision within most local authorities in the UK has a profound impact on the lives of people with Asperger syndrome and their families.

Furthermore, it is essential that health and social services work together. For example, if a local authority decides that learning disability social services teams will take the lead for initial assessment of need for community care, then they should have access to health colleagues and services in the local NHS trust.

**65% of adults with an autistic spectrum disorders have never been offered a community care assessment.**

**(Barnard et al, 2001)**

## Service needs

Once local authorities have decided who is responsible for community care assessment, it will be easier to develop services. Audits of need are an essential priority for service provision.

Whilst Asperger syndrome is a complex condition, it is clear that some ways of working are more helpful than others as described in this document.

Services will develop as our evaluated research knowledge increases but in the meantime we should pay heed to the voices of people with Asperger syndrome, their families and practitioners. The services they have consistently requested should now be implemented:

1. A training programme to increase professional awareness and understanding across a wide range of community services including social, health, housing, school and continued education, employment and Connexions services.
2. A clear support pathway so families know whom they can contact to request assessment regarding possible diagnosis.
3. A clear support pathway so families know whom they can contact to request assessment under *The NHS and Community Care Act 1990*.
4. An improvement in employment opportunities and support.
5. Preventative interventions to reduce social isolation.
6. Interventions to reduce clinical mental health difficulties.
7. Interventions to develop independent living skills and relationships.
8. Better post-diagnosis emotional support, information and advice for people with Asperger syndrome.
9. A range of appropriate supported housing options.

**Only 3% of adults with Asperger syndrome live fully independent lives.**

**(Barnard et al, 2001)**

10. Better social and academic support and learning opportunities within secondary schools, during transition, college or university.
11. Carers' needs assessed and met, including education/information/advice, counselling (including genetic counselling) and 'respite' type services, such as befriending for their sons and daughters.
12. More appropriate service provision. Many adults are placed in services that are not suitable for Asperger syndrome, due to poor provision or misdiagnosis.
13. Access to advocacy services for families and people with Asperger syndrome.
14. Sensitive crisis services (not necessarily mental health in-patient).
15. Forensic services (to support the few people who display behaviour likely to put themselves or others at risk of harm).

## **Saving costs**

Apart from the very obvious human cost, the lack of decision making in local social and health care services represents a waste of public resources.

Comprehensive assessment of need and a low level of support from social and health care services can make the difference between successfully living an independent life and suffering mental health problems requiring medication and intensive support. Pro-active support before real difficulties occur will save local authorities and health trusts money in the long term.

The estimated annual expenditure on services for people with autistic spectrum disorders in the UK is approximately £1bn. Only 7% is spent on education. The bulk of the cost is taken up paying for long-term care (Knapp and Jarbrink, 2000). The other hidden costs are the people caught up in the criminal justice system and mental health units.

Since much health input will be around advice and assessment, joint working need not be seen as costly, especially if input occurs before difficulties begin.

If increased social education support, such as social groups, post-diagnostic support, self-advocacy and life skills were given to teenagers and adults with Asperger syndrome, more would be able to live with greater independence and at a reduced public cost.

*The time to provide appropriate support and understanding is well overdue. The National Autistic Society continues to offer its expertise and experience to any local service that takes the opportunity to develop and improve provision for people with Asperger syndrome.*

# Appendix A

## UK Asperger syndrome/autistic spectrum disorder research and local audit reports

Beardon, L. (1998) *Sheffield Autism Services Development Project*. Nottingham: National Autistic Society.

Brogan, C. (2001) *Greater Glasgow Autism Project: people with autistic spectrum disorders aged 12 to 30*. Scotland: National Autistic Society.

Jackson, C. (1998) *Needs of people with autism in South Buckinghamshire*. High Wycombe: Buckinghamshire County Council and Buckinghamshire Health Authority.

Jarrett, S. (1998) *The most complex group: a report on the needs of Autistic Spectrum children and adults and their families in Harrow*. London: National Autistic Society Harrow Branch.

Jarrett, S. (2000) *Facing up to Autism: a report on the needs of Autistic Spectrum children and adults in Brent*. London: National Autistic Society Brent Branch.

Knight, L. and Porter, I. (2001) *Asperger syndrome Needs Assessment Study*. Liverpool: North Mersey Community NHS Trust.

Leadbeater, C. (2000) *Identifying the needs of adults with Asperger syndrome in Northamptonshire*. Northampton: National Autistic Society.

Moochan, R. (2000) *Asperger syndrome in Barnet: A report on the needs of people with Asperger syndrome*. London: London Borough of Barnet.

Moore, P. (1997) *Acknowledging Autism*. Taunton: Somerset County Council.

Nesbitt, S. (1999) *Autism Research Project, May 1999 – Joint Commissioning Group for Children with Disabilities*. London: London Borough of Hounslow.

Parsons, J. (2000) *Analysing needs and reviewing services for children and adults with Autistic spectrum disorders in South Staffordshire*. Stafford: Staffordshire County Council.

Plowes, N. (1998) *Family services work in Bradford 1995-1998*. Nottingham: National Autistic Society.

Portway, S. (2000) *The needs of children and adults with Asperger syndrome living in Berkshire, Report of the Berkshire Asperger Research Project*. Reading: Berkshire Autistic Society.

Powell, A. (2000) *Active Intervention: Full Interim report – Avon Asperger Syndrome Project Report*. Bristol: National Autistic Society.

Forthcoming Asperger syndrome specific research projects:

Ting Chen  
Research Assistant  
School of Health and Related Research  
University of Sheffield in conjunction with  
Sheffield Community Health NHS Trust  
Sheffield  
(0114 271 6383)

Fiona Burns  
Assistant Psychologist  
Surrey Oaklands NHS Trust  
Clarendon House  
28 West Steet  
Dorking Surrey RH4 1QJ  
(01306 502 409)

## Appendix B

# Asperger syndrome organisations

The following list is of individuals and organisations that aim to support people with Asperger syndrome. It is not an exhaustive list, nor is it necessarily a list of recommendation.

Action ASD, Lancashire 01706 222 657

Asperger Syndrome Professionals Network (ASPEN) National Autistic Society, Nottingham 0115 911 3360

Asperger's Advisory Line, David Moat 01206 525 980

Asperger Back-up Campaign (raising awareness of the needs of 'partners', information): contact The National Autistic Society for details

*Asperger United* (a magazine by and for people with Asperger syndrome) 0207 903 3595

Autism Accreditation (National Autistic Society) 0117 974 8429

Autistic Society for the Greater Manchester Area (ASGMA). (Aspirations – social activity groups, age 16-25) 0161 793 1323

Autism Independent UK (mostly education and training providers) 01536 523 274.

Autism Initiatives (family support, residential and day care, outreach) 0151 3309 500

Autism Tasc Services 01782 658156

Avon Asperger Syndrome Project 1999-2002. National Autistic Society, Bristol 0117 974 8420 (until August 2002)

Asperger Norfolk (social groups and a range of services) 01603 620 500

BBI (London based long term lifestyle support) 020 8677 6550

Breakthrough (Asperger syndrome drop in and information resource for families and professionals in North Somerset) 01275 878 034

Bromley Autistic Trust (Social groups and a range of services) 01689 857 886

Burnham Service (National Autistic Society) Residential care and supported housing 01278 792 962

Cambridge Lifespan Asperger syndrome Service (CLASS) a national diagnostic service for adults 01223 746 109

Centre for Social and Communication Disorders, Elliot House, Bromley, Kent (diagnosis assessment and training) 020 8466 0098

County Durham Autistic Support Group (advice and information) 01388 819 880

Disabilities Trust, Berkshire (Dee Constable, Dyson's Wood House) 0118 972 4553

European Services for People with Autism (ESPA). Range of Further Education provision  
0191 567 3523

Farleigh Education Group (schools and further education provision) 01373 463 172

Hampshire Autistic Society (ASPIN House, 16-19 provision, including lifeskills) 023 8090 0905

Hesley Group (schools, information). Southern office 01590 624484

Hill Park Housing Association, London (Frank House for adults with Asperger syndrome)  
020 8319 5783

Glasgow Nautical College, Transitions programme, a life-skills programme for people not yet  
ready for a vocational college course 0141 565 2806

Gloucestershire Group Homes (residential, day and outreach service for adults) 01453 835 023

Hayes Unit (National Autistic Society) for model in meeting needs of adults in secure setting  
01454 632 311

*help!* is the National Autistic Society Post-diagnostic programme of information advice and support  
for parents. (UK *help!* Programme Manager) 0117 974 8400

Hoffman de Visme Foundation, London (accommodation, outreach and counselling)  
020 8341 1931

Hyndburn Service (National Autistic Society) for model of tiered housing support for people with  
Asperger syndrome and social services involvement 01254 888 535

Independent Community Living, Caerphilly (residential and day services) 029 2088 1994

Interact Centre, a model of further education provision for people who require some life skill  
training before going into a vocational college placement 020 8575 0046

John Mortlock Ltd (training provider) 01424 439 691

Kent Autistic Trust. Family support officer (information, advice) 01634 405 168

Leicestershire Autistic Society (Monday Club, social and independent living skills group, 18+)  
01455 448144 (evenings)

National Autistic Society Autism Helpline (for people with Asperger syndrome and their families)  
0870 600 8585 (Mon – Fri 10.00 – 16.00)

National Autistic Society guidelines on 'social groups'. Director of Development 0115 911 3360

National Autistic Society Information Centre (for professionals) 020 7903 3599  
(Mon – Fri 10.00 – 14.00)

National Autistic Society New Ground service to develop work based skills, including horticulture, carpentry, office skills 01633 866 339

National Autistic Society Training and Consultancy Services 0115 911 3363

National Autistic Society Volunteering and Befriending Manager 0115 911 3369

National Initiative on Autism: Screening and Assessment (NIASA): contact National Autistic Society Information Centre for details 020 7903 3599

Northamptonshire Adult Social Group for people with Asperger syndrome 01933 279 518

Nottingham Regional Society for Autistic Children and Adults (NoRSACA) 0115 987 3655 (Social activities group and befriending)

Oxford Autistic Society for Information and Support 01865 750160

Partners (Contact for partners of people with Asperger syndrome) National Autistic Society 020 8752 9610

Ruskin Mill Education Centre (further education) 01453 837500/837521

St George's Hospital Medical Centre, London (diagnosis and assessment) 020 8672 1255

SACAR, Bradford (social awareness training, for local service users) 01274 424621

S.A.F.E. (Supporting Asperger Families in Essex) 01206 240 931

Sheffield Counselling Service for people with Asperger syndrome 0114 230 2550

Southlands school, Lymington (school and post 16 provision) 01590 675 350

Spectrum (services) 01872 279 198

Stop Gap – Herts Careers Service (lifeskills training for young people with Asperger syndrome) 01707 281411

Sussex Autistic Society (Mon – Thurs 10.00-12.30) 01273 841 254

TRACS, Wales (residential, day and outreach services) 01792 459 571

Wargrave House School (5-19 provision, autistic spectrum disorder, some Asperger syndrome) 01925 224 899

Wessex Autistic Society (community outreach, supported housing) 01202 483360

West Midlands Autistic Society, (employment support, social groups, supported housing) 0121 472 4895

Wirral Asperger Syndrome Parents Support (WASPS) 0151 653 8877

Wirral Autistic Society, 0151 334 7510 (wide range of services)

Yates, Pam (independent consultant in Asperger Syndrome and autism) 020 8832 9213

## Bibliography

American Psychiatric Association (1994) *Diagnostic and statistical manual of mental disorders (DSM-IV)*. 4th edition. Washington DC: American Psychiatric Association.

Aston, M. (2001) *The other half of Asperger syndrome*. London: National Autistic Society.

Attwood, T. (1998) *Asperger's syndrome*. London: Jessica Kingsley Publishers.

Audit Commission (1999) *Children in mind: child and adolescent mental health Services*. London: Audit Commission.

Autism Accreditation (2002) *Membership register*. Issue 29, April 2002. Bristol: National Autistic Society.

Baird, G. et al (2000) A screening instrument for autism at 18 months of age: a 6 year follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, vol 39, pp. 694-702.

Barnard, J., Broach, S., Potter, D. and Prior, A. (2002) *Autism in schools: crisis or challenge?* London: National Autistic Society.

Barnard, J., Harvey, V., Prior, A. and Potter, D. (2001) *Ignored or ineligible? The reality for adults with autism spectrum disorders*. London: National Autistic Society.

Barnard, J., Prior, A. and Potter, D. (2000) *Inclusion and autism: is it working?* London: National Autistic Society.

Baron-Cohen, S., Leslie, A.M. and Frith, U. (1985) Does the autistic child have a 'theory of mind'? *Cognition*, 21, pp.37-46

Barrett, P. and Thomas, B. (1999) The inclusion of students with Asperger syndrome in a mainstream secondary school: a case study, *Good Autism Practice*, September, pp.65-71.

Beardon, L. (1998) *Sheffield Autism Services Development Project*. Nottingham: National Autistic Society.

Brogan, C. (2001) *The pathway to care for children with autistic spectrum disorders (aged 0 to 12 years)*. Glasgow: National Autistic Society.

Brogan, C. (2001) *Greater Glasgow Autism Project: people with autistic spectrum disorders aged 12 to 30*. Glasgow: National Autistic Society.

Carpenter, P. (1999) The use of medication to treat mental illness in adults with autistic spectrum disorders. Personal communication.

Carrington, S. and Graham, L. (2001) Perceptions of school by two teenage boys with Asperger syndrome and their mothers: a qualitative study, *Autism*, vol 5(1) pp. 37-48.

Chakrabarti, S. and Fombonne, E. (2001) Pervasive developmental disorders in preschool children. *JAMA*, vol 285, pp. 3093-3099.

Cumine, V., Leach, J. and Stevenson, G. (1998) *Asperger syndrome – a practical guide for teachers*. London: David Fulton.

Department for Education and Skills (2001) *Special Educational Needs: Code of Practice*. Annesley: Department for Education and Skills.

Department of Health (1990) *Community Care in the next decade and beyond: policy guidance*. London: HMSO.

Department of Health and Home Office (1992) *Review of health and social services for mentally disordered offenders and others requiring similar services*, Dr John Reed, vol 7 – people with learning disabilities (mental handicap) or autism. London: HMSO.

Department of Health/SSI (1998) *Moving into the mainstream – an inspection of services for adults with learning disabilities*. London: Department of Health.

Department of Health (2000) *Framework for assessment of children and their families*. London: Stationery Office.

Department of Health (2001) *A practitioner's guide to carers' assessments under the Carers and Disabled Children Act 2000*. London: Stationery Office.

Department of Health (2001) *Health and Social Care Act 2001*. London: Stationery Office.

Department of Health, (2001) *Valuing people – a new strategy for learning disability for the 21st century*. London: Stationery Office.

Department of Health, (2001) *Valuing people – a new strategy for learning disability for the 21st century: Implementation*. London: Department of Health.

Department of Health and Connexions (2001) *Working together: social services and Connexions*. London: Stationery Office.

Ehlers, S. and Gillberg, C. (1993) The epidemiology of Asperger syndrome. A total population study. *Journal of Child Psychology and Psychiatry*, 34(8), pp. 1327-1350.

English, A. and Essex, J. (2000) *West Midlands Report on autistic spectrum disorders : Executive Summary*. Warwick: Warwickshire County Council for the SEN Regional Partnership.

Evans, J. (1999) *Can children with autistic spectrum disorders be included in mainstream?* Slough: National Foundation for Educational Research.

Gillberg, I.C. and Gillberg, C. (1989) Asperger syndrome – some epidemiological considerations. A research note. *Journal of Child Psychology and Psychiatry*, vol 30, pp. 631-638.

Gray, C. (2001) *From both sides now: how to teach social understanding*. Jenison, Michigan: The Gray Center for Social Learning and Understanding.

Gray, C. (1999) *Gray's guide to compliments: introducing the first social workbook*. *The Morning News* vol 11 (1). Jenison, Michigan: Jenison Public Schools.

- Gresley, L. (2000) *Cognitive adaptation to the diagnosis of Asperger syndrome and the relationship with depression and adjustment*. Unpublished Phd thesis. University of Exeter
- Hand, M. (1999) Developing a strategy for autism in one local authority, a collaborative approach: the first eighteen months. *Good Autism Practice*, September, pp. 1-11.
- Happé, F. (1994) *Autism: an introduction to psychological theory*. London: UCL Press.
- Hare, D. J. (1997) The use of cognitive behavioural therapy with people with Asperger syndrome, *Autism*, vol 1(2) pp. 215-225.
- Hare, D.J. et al (2000) *Asperger syndrome in a high security hospital*. London: National Autistic Society.
- Hare, D.J. and Flood, A. (2001) Approaching work with people with a diagnosis of Asperger's syndrome: some notes for the perplexed. *Clinical Psychology Forum*, 147, January.
- Hertfordshire Careers Services (2001) *Stop-Gap Project information pack*. Hertfordshire County Council.
- Heslop, P. et al (2001) *Bridging the divide – the experiences of young people with learning difficulties and their families at transition*. Bristol: Norah Fry Research Centre.
- Hobson, R.P. (1993) *Autism and the development of mind*. Hove: L. Erlbaum Associates.
- Holland, T. et al. (2001) *Current Issues surrounding the diagnosis, management, treatment of children and adults with Asperger's Syndrome*. Cambridge: Department of Psychiatry, University of Cambridge.
- Howlin, P. (1997) *Autism – preparing for adulthood*. London: Routledge.
- Howlin, P. (2000) Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism*, vol 4(1) pp. 63-83.
- Howlin, P. and Moore, A. (1997) Diagnosis in autism – a survey of over 1200 patients in the UK. *Autism*, vol 1(2) pp.135-162.
- Howlin, P. and Yates, P. (1999) The potential effectiveness of social skills groups for adults with autism: information update. *Autism*, vol 3(3) pp. 299-307.
- Inter-Departmental Review of Funding for Supported Accommodation (1998) *Supporting people: a new policy and funding framework for support services*. London: Department of Social Security.
- Jackson, C. (1998) *Needs of people with autism in South Buckinghamshire*. High Wycombe: Buckinghamshire County Council and Buckinghamshire Health Authority.
- Jarbrink, K. and Knapp, M. (2000) The cost of autistic spectrum disorder report, *Update*, vol 1. Issue 17. Mental Health Foundation.
- Jarrett, S. (1998) *The most complex group: a report on the needs of Autistic Spectrum children and adults and their families in Harrow*. London: National Autistic Society Harrow Branch.

Jarrett, S. (2000) *Facing up to Autism: a report on the needs of Autistic Spectrum children and adults in Brent*. London: National Autistic Society Brent Branch.

Jones, A. (2000) *Protocol for meeting clinical and social needs of individuals with developmental disorders which include Asperger syndrome in East Cheshire*. Personal communication.

Jones, G. (2000) Accredited Courses on Autism. *Good Autism Practice*. vol.1(1) p.73.

Jordan, R. and Powell, S. (1995) *Understanding and teaching children with autism*. Chichester: John Wiley and sons.

Kadesjö, B. Gillberg, C. and Hagberg, B. (1999) Brief report: autism and Asperger syndrome in seven year old children: a total population study. *Journal of Autism and Developmental Disorders*. vol 29 (4) pp. 327-331.

Knight, L. and Porter, I. (2001) *Asperger syndrome needs assessment study*. Liverpool: North Mersey Community NHS Trust.

Konig, C. and Magill-Evans, J. (2001) Social and language skills in adolescent boys with Asperger syndrome, *Autism*, vol.5(1) pp. 23-36.

Lawson, W. (1998) *Life behind glass: a personal account of autistic spectrum disorder*. London: Jessica Kingsley Publishers.

Leadbeater, C. (2000) *Identifying the needs of adults with Asperger syndrome in Northamptonshire*. Northampton: National Autistic Society.

Lord, C., Rutter, M. and Le Couteur, A. (1994) Autism Diagnostic Interview – Revised: a revised version of a diagnostic interview for carers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*. vol 24, pp. 659-685.

Loynes, F. (2000) *The impact of autism (Report for the All Party Parliamentary Group on Autism)*. London: All Party Parliamentary Group on Autism.

Loynes, F. (2001) *The rising challenge: a survey of educational provision for pupils with autistic spectrum disorders*. London: All Party Parliamentary Group on Autism.

MacLeod, A. (1999) The Birmingham community support scheme for adults with Asperger syndrome. *Autism*, vol 3(2) pp.177-192.

Mandelstam, M. (1999) *Community care practice and the law*. 2<sup>nd</sup> ed. London: Jessica Kingsley Publishers.

Mawhood, L and Howlin, P. (1999) The outcome of a supported employment project for high-functioning adults with autism or Asperger syndrome. *Autism*, vol. 3 (3) pp. 229-234.

Medical Research Council (2001) *Review of autism research: epidemiology and causes*. London: Medical Research Council.

Moochan, R. (2000) *Asperger syndrome in Barnet: A report on the needs of people with Asperger syndrome*. London: London Borough of Barnet.

- Moore, P. (1997) *Acknowledging autism*. Taunton: Somerset County Council.
- Mountford, K. (1999) *Why isn't it there?: Commissioning appropriate services for people with autistic spectrum disorders*. Paper from Conference proceedings. *Autism: DNA to day-to-day living*. Brighton: Pavilion.
- National Autistic Society (1994) *Autism: the invisible disability*. London: National Autistic Society.
- National Autistic Society (1996) *Beyond Rainman*. London: National Autistic Society.
- National Autistic Society (2000) *Greater Manchester Consortium to develop local services for people with autism: working together towards a regional strategy. Report on the second regional convention*. Manchester: National Autistic Society.
- Nesbitt, S. (1999) *Autism Research Project, May 1999 – Joint Commissioning Group for Children with Disabilities*. London: London Borough of Hounslow.
- Oliver, M. (1990) *The politics of disablement*. London: Macmillan.
- Parsons, J. (2000) *Analysing needs and reviewing services for children and adults with autistic spectrum disorders in South Staffordshire*. Stafford: Staffordshire County Council.
- Peacock, G. Forrest, A. and Mills, R. (1996) *Autism – the invisible children?* London: National Autistic Society.
- Peter, M. (2000) *Developing drama with children with autism*, *Good Autism Practice Vol 1 (1)* pp. 9-20.
- Plowes, N. (1997) *Family services work in Bradford 1995-1998*. Nottingham: National Autistic Society.
- Portway, S. (2000) *The needs of children and adults with Asperger syndrome living in Berkshire, Report of the Berkshire Asperger Research Project*. Reading: Berkshire Autistic Society.
- Powell, A. (2000) *Active Intervention: Full Interim report – Avon Asperger Syndrome Project Report*. Bristol: National Autistic Society.
- Proceedings of second conference on Developmental Neuropsychiatry and learning disability: Asperger syndrome* (2000) Norwich: Norwich Community Health Partnership.
- Public Health Institute of Scotland (2001) *Autistic spectrum disorders – needs assessment report*. Glasgow: PHIS/NHS Scotland.
- Rinaldi, W. (1992) *The social use of language programme*. Windsor: NFER-Nelson.
- Sainsbury, C. (2000) *Martian in the playground*. Bristol: Lucky Duck.
- Sainsbury, C. (2002) *Speaking for ourselves: the emerging voices of people with Asperger syndrome/high-functioning autism. Personal communication*.

- Searle, G.F. (1999) Asperger's syndrome on the context of general adult psychiatry, Paper from conference proceedings – *Autism: DNA to day-to-day living*. Brighton: Pavilion.
- Shah, A. (1999) Asperger syndrome – behaviour issues, a psychological approach. Paper from proceedings of conference – *Asperger syndrome: diagnostic and management issues, looking beyond childhood*. Brighton: Pavilion.
- Simons, K. (2001) *Strategies for change. Developing housing and support options. (Briefing paper)*. Bristol: Norah Fry Research Centre.
- Sinclair, J. (1993) Don't mourn for us. *Our Voice*, vol 1(3).
- Slater-Walker, G. and C. (2002) *An Asperger marriage*. London: Jessica Kingsley Publishers.
- SSI, SWSG (1991a) *Care Management and Assessment: Practitioners Guide*. London: HMSO.
- SSI, SWSG (1991b) *Care Management and Assessment: Managers Guide*. London: HMSO.
- SSI (1995a) *A way ahead for carers, priorities for managers and practitioners: a summary of two SSI reports*. London: Department of Health.
- Stirling, A. and Prior, A. (1999) *Opening the Door*. London: National Autistic Society.
- Tantam, D. (1991) Asperger syndrome in adulthood, in *Autism and Asperger syndrome*, Frith, U. (ed), Cambridge University Press.
- Tantam, D. (2000) Psychological disorder in adolescents and adults with Asperger syndrome, *Autism*, vol. 4 (1), pp 47-62.
- Thompson, A. (2000) Falling through the gap. *Community Care*, 30 March, pp. 20-21.
- Thrower, D. (2000) *Local monitoring by health authorities of childhood autism Incidence in the UK*, Warrington, unpublished.
- Vermeulen, P. (2001) *Autistic thinking – this is the title*. London: Jessica Kingsley Publishers.
- Whitaker, P et al. (1998) Children with autism and peer group support: using 'circles of friends'. *British Journal of Special Education*, vol 25(2), pp. 60-64.
- Willey, L. H.(1999) *Pretending to be normal*. London: Jessica Kingsley Publishers.
- Williams, D. (1992) *Nobody nowhere*. London: Jessica Kingsley Publishers.
- Wing, L. (1981) *Asperger syndrome: a clinical account*. London: National Autistic Society.
- Wing, L. (1993) The definition and prevalence of autism: a review. *Journal of European Child and Adolescent Psychiatry*. Vol.2(2) pp.61-74.
- Wing, L. (1996) *The autistic spectrum*. London: Constable.
- Wing, L. (1998) Foreword in T. Attwood *Asperger's syndrome*. London: Jessica Kingsley Publishers.

Wing, L. and Gould, J. (2002) The Diagnostic Interview for Social and Communication Disorders: Background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry*. vol 43(3) pp 307-325.

Wolff, S. and McGuire, R.J. (1995) Schizoid personality in girls: a follow up study, what are the links with Asperger syndrome?. *Journal of Child Psychology and Psychiatry*, Vol 36, pp. 793-818.

World Health Organisation (1992) *ICD-10 International Classification of diseases and related health problems*. Geneva: World Health Organisation.



**The National Autistic Society has regionally based Development teams offering advice and support to local authorities and health trusts in the development of services for people with autistic spectrum disorders. For your local contact please ring 0115 911 3360.**

**The National Autistic Society**  
**393 City Road**  
**London EC1V 1NG**  
**Tel: 020 7833 2299**  
**Minicom: 020 7903 3597**  
**Fax: 020 7833 9666**  
**Em: [nas@nas.org.uk](mailto:nas@nas.org.uk)**  
**Website: [www.nas.org.uk](http://www.nas.org.uk)**

**NAS Scotland**  
**Central Chambers**  
**109 Hope Street**  
**Glasgow G2 6LL**  
**Tel: 0141 221 8090**  
**Fax: 0141 221 8118**  
**Em: [scotland@nas.org.uk](mailto:scotland@nas.org.uk)**

**NAS Wales**  
**William Knox House, Suite C1**  
**Britannic Way, Llandarcy**  
**Neath SA10 6EL**  
**Tel: 01792 815915**  
**Fax: 01792 815911**  
**Em: [wales@nas.org.uk](mailto:wales@nas.org.uk)**