

**A Review of the Needs and Services for 10-18 year-old
Children and Young People diagnosed with Asperger
Syndrome living in Northern Ireland**

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February 2007

Commissioned by
The Northern Ireland Commissioner for Children
and Young People (NICCY)

ACKNOWLEDGEMENTS

There are several groups of people who worked on this Review together with the Autism Team from the University of Birmingham whom we would like to thank for their views and commitment.

Thanks to all those from NICCY, and particularly to Helen Beckett who managed the project, and to:

Louise Benson, NICCY;
Teresa Devlin, NICCY;
Linda Kerr, NICCY; and
Chantal Standley, NICCY.

Thanks to other members of the Steering Group for their advice and guidance:

Jackie Addis, Autism NI;
Sharon Doherty, Asperger's Network;
Paula Hanratty, Autism NI;
Fiona McCaffrey, Autism NI;
Lorraine Milne, Parent; and
The two young people who acted as consultants to the Review.

Thanks to the parents, professionals and young people within:

Asperger's Network;
Autism NI;
Autism Initiatives;
Department of Education
Education Library Boards;
Health and Social Services Boards;
Employment for Autism;
Special Interest Group;
Independent Psychology Services; and
All staff in the schools and colleges who completed the questionnaires.

Thanks to Linda Hudson at the University of Birmingham for her secretarial support to this Review and for sending out and collating the questionnaires and inputting the data.

Finally, many thanks to all the parents and carers, and the children and young people with Asperger syndrome themselves for completing the questionnaires and sharing their views with the Review Team. The time and effort given by all to this Review has been very much appreciated.

Autism Team
University of Birmingham
October 2006

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GLOSSARY OF TERMS

Abbreviation	Definition
ADHD	Attention Deficit Hyperactivity Disorder
ADOS	Autism Diagnostic Observation Schedule
AI	Autism Initiatives
ANI	Autism Northern Ireland (formerly PAPA)
AS	Asperger Syndrome
ASD	Autistic Spectrum Disorder
CA	Classroom Support Assistant
CBT	Cognitive Behavioural Therapy
CP	Clinical Psychologist
DDA	Disability Discrimination Act
DE	Department of Education
DES	Department of Education and Science
DfES	Department for Education and Skills
DISCO	Diagnostic Interview for Social and Communication Disorders
DLA	Disability Living Allowance
EP	Educational Psychologist
ETI	Education and Training Inspectorate
FE	Further Education
HE	Higher Education
HFA	High Functioning Autism
GP	General Practitioner
ICT	Information and Communications Technology
IEP	Individual Education Plan
NAPC	National Autism Plan for Children
NES	NHS Education for Scotland
NHS	National Health Service
NIASA	National Initiative for Autism Screening and Assessment
PAPA	Parents and Professionals and Autism (now Autism NI or ANI)
SALT	Speech and Language Therapist
SEN	Special Educational Needs
SENCo	Special Educational Needs Coordinator
SIG	Special Interest Group
SIGN	Scottish Intercollegiate Guidelines Network

EXECUTIVE SUMMARY

This executive summary presents the main findings of the Review, and makes recommendations which arise from the data collected and from the literature and guidance on Asperger syndrome (AS) produced within Northern Ireland and in the rest of the UK.

SECTION 1: INTRODUCTION TO THE REVIEW

1.1 Aims of the Review

- To identify the needs of young people with Asperger syndrome who are aged between 10 and 18 years and living in Northern Ireland; and
- To identify what services are currently provided for these young people and their families, and how these might be further enhanced.

1.2 Definition of Autism Spectrum Disorder and Asperger Syndrome

Autism spectrum disorder (ASD) is the umbrella term for a range of conditions that have a common core of difficulties. Autism spectrum disorder covers the three main categories of:

- Autism (autistic disorder);
- Asperger syndrome (disorder); and
- Pervasive developmental disorder, not otherwise specified (PDD-NOS; atypical autism).

Individuals with AS are different from one another, perhaps even more so than typical children, as their difficulties in learning through social means result in their exclusion (at least partly) from a shared, cultural view of the world. In spite of individual differences between individuals with AS, they share a common core of difficulties that

define those with ASD and differentiate them from other conditions. This commonality lies in a core set of developmental differences that were first identified by Wing (1988) and have come to be known as the '*triad of impairments*'.

Different versions of this exist, but an accepted version (Jordan, 1999) identifies difficulties in:

- *Social and emotional* understanding;
- All aspects of *Communication*; and
- *Flexibility* in thinking and behaviour.

Different subgroups have been described in the literature including high functioning autism and semantic pragmatic disorder. Debate and discussion continues on the existence and the distinctions between categories and subgroups under the heading of autism spectrum disorder and these are not always clear cut (Bishop, 1989; Kugler, 1998). In addition, deciding where the cut-off point might be between 'typical development' and an ASD is challenging, and it may be hard in the cases of some children and young people to determine the diagnosis and/or to decide whether there are benefits to giving the diagnosis (Barrett et al., 2004). Most would agree that a formal diagnosis is usually given to those whose differences and difficulties are such that they significantly interfere with their functioning in everyday life. Children and young people with AS included in this Review are those where parents and professionals have recognized that they require additional or different support from their peers.

1.2.1 Diagnosis of Asperger Syndrome

There are two major diagnostic classification systems in use. One is the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) and the other is the International Classification of Diseases, Version 10 (ICD-10), which is the most often used in the UK. Each has similar criteria for the diagnosis of autism based on the triad of impairments and ICD-10 lists criteria for a diagnosis of Asperger syndrome (see **Appendix 1**), where the behaviours are discrepant from the mental age of the

individual. These criteria have changed over the years and will continue to change as understanding of the condition develops.

For a diagnosis of Asperger syndrome, there should have been no significant delay in the development of speech and the child or young person should not be intellectually impaired. He or she will be within, or above, the average range of intelligence. Those involved in diagnostic assessment do not always strictly follow these criteria and so there are some individuals who have had delayed speech and language and who are below average intellectual ability but who have been given the diagnosis of Asperger syndrome. This confuses the picture for professionals and parents alike.

Agreeing on and confirming the diagnosis is not always an easy process and it is possible for misdiagnosis to occur because there is no definitive medical, biological or psychological test that can confirm the diagnosis of Asperger syndrome. Diagnosis is made on the basis of the behaviours observed and reported by parents and others. It is therefore subjective and dependent on the personal opinions and skills of the different professionals who see the child or adult. There are agreed lists of criteria for autism and Asperger syndrome in Appendix 1 which diagnosticians need to use as a guide and on which diagnostic instruments are based, but it can be hard to reach a consensus of opinion on whether a child or adult meets some of these, as they are based on behaviours seen or reported.

In some of the literature, there are misleading statements to the effect that individuals with AS have a 'mild form of autism'. This opinion has been given on the basis that children and adults with AS are of average or above intelligence and have good speech and language skills. But it is not necessarily the case that the nature and impact of their difficulties is mild. Further discussion on Asperger syndrome can be found in Section 2.1 of this Review.

1.3 Purpose of this Review

The purpose of this Review is to identify the needs of children and young people with Asperger syndrome, who are aged 10 to 18 years and living in Northern Ireland, from

their own perspective and from their parents' and carers' perspective. In addition, the views of professionals in Education, Health and Social Services and those working in voluntary organisations who are working to ascertain and address these needs will be reported.

The Review will be a resource for all those working and living with children and young people with Asperger syndrome. It aims to provide evidence on current guidance and practice in Northern Ireland, making reference also to the literature and practice elsewhere in the UK.

1.4 Methods of data collection

During the period January to June 2006:

- A Literature Review was undertaken on current literature and research relating to Asperger syndrome and on policy, legislation and guidance in Northern Ireland.
- Questionnaires were devised and circulated to:
 - Children and young people with Asperger syndrome;
 - Parents/carers of children and young people with Asperger syndrome;
 - Mainstream and special schools and colleges; and
 - Providers of services.
- Interviews were held face-to-face or by telephone with parents, health professionals, social workers and children and young people with AS.
- Data which had been collected by the Department of Education on the numbers of pupils with Asperger syndrome were analysed.

SECTION 2: LITERATURE REVIEW

The Literature Review considers current understandings of Asperger syndrome and reviews the issues, practice and national guidance in Northern Ireland, the rest of the UK and elsewhere, relating to how the needs of children and young people with AS and their families might be addressed and met effectively.

SECTIONS 3 TO 8: MAIN FINDINGS

These findings are based on the Literature Review conducted on current research, guidance and practice in the field of Asperger syndrome in the UK and elsewhere, and on the data provided by parents, professionals, voluntary organisations and young people with AS themselves, living in Northern Ireland.

Note

Where the finding arises from the data, the Section number of where these data can be found in the report is given alongside.

3.1 Numbers of children and young people aged 10 to 18 years with a diagnosis of Asperger syndrome living in Northern Ireland

FINDING 1: (from the literature)

It is not possible, given current diagnostic practice and the instruments and methods of recording Asperger syndrome, to establish the exact numbers of children and young people with Asperger syndrome living in Northern Ireland, or in other areas of the UK or the world.

FINDING 2: (from data, Section 3.2)

The Department of Education in Northern Ireland collects data from all schools on the numbers of pupils with Asperger syndrome on roll. This is an extremely useful database for monitoring and planning purposes

FINDING 3: (from data, Section 7)

Currently, those working in different agencies and services often keep their own database on children and young people with AS, so that within the same

geographical area, there may be several registers or databases held by Education, Health, Social Services or a voluntary organisation on which the same children and young people might appear.

Recommendation 1:

It would be very helpful to create just one database within a geographical area to which all agencies in health, education and social services contribute and to which they all have access. There are some serious ethical and logistical issues to resolve here, so as yet, it remains a desirable but distant goal. The Department of Education has a single database for all children with Asperger syndrome with SEN in the school sectors which is available by geographical area and Board area.

3.2 Regional differences which exist

FINDING 4: (from literature and data in Section 5)

Services offered to families of children and young people with AS vary depending on the area in which they live, but much energy has been put in to providing resources and services in many areas of Northern Ireland to enhance these, and to disseminate good practice. It is likely, then, that services to families and individuals with AS will become more consistent geographically and comprehensive in future years.

3.3 Practice in mainstream schools and colleges

FINDING 5: (from data in Section 6)

The majority of respondents in Northern Ireland mentioned improvements in the last three years in what was now offered to children with AS and HFA within schools and colleges. There were very few school/college respondents who said they felt very unsupported. For parents too, school or college was often the only area of life where they felt their children were being supported, although some had had to change the school or college placement because their first choice had proved 'disastrous'.

FINDING 6: (from data in Section 3)

One of the issues in improving services for the identification of AS is that more individuals with AS are then discovered to be in need of a service, and so the number of professionals who need specific training and responsibility for these children has also increased. The relatively newly-established ELB ASD Advisory Teams are therefore being stretched to meet current needs.

Recommendation 2:

For education, health and social care to consider how the caseloads of those with posts with specific responsibility for ASD are best managed and their resources used effectively to meet needs. The Department of Education is currently carrying out a review of SEN and Inclusion, which will consider the management and use of Board resources.

Recommendation 3:

For those in education, health, social care and the voluntary sector who have a brief for training, to audit the training available, received and required in their area. The Department of Education review of SEN and Inclusion is to consider future models for Board training.

3.4 Diagnosis, assessment and interventions in Asperger syndrome

FINDING 7: (from the literature)

There is now a broad consensus arising from national documents developed in the UK on how a diagnostic assessment should be carried out and what should follow. Multidisciplinary assessment by a local team of professionals with specific training in ASD is recommended, together with training for primary health care professionals in the alerting signals of ASD.

FINDING 8: (from data in Sections 5 and 7)

Many parents in Northern Ireland in this survey complained about the long delay in getting the diagnosis either because the condition was not recognised by the

professionals they met and/or because of the long waiting lists that exist. Professionals interviewed had very similar concerns and were trying their best to improve matters. In Northern Ireland and elsewhere, it is the case that some children with AS are not diagnosed until late primary or post-primary age (or adulthood), even when evidence of AS in their early years has been clear.

FINDING 9: (from data in Section 5)

Some families in Northern Ireland pay privately for diagnostic assessments (and in some cases, continuing intervention) from psychologists working independently, and parents are often very pleased with this service, apart from the financial costs. In Northern Ireland and the rest of the UK, there is a realisation that some families find it easier to access services and support than other families due to factors such as location, transport, literacy levels, ethnicity, and social class.

It is probable that 'advantaged' families in Northern Ireland are more likely to receive a diagnosis of AS than other families and at an earlier age. All services need to review how well they deliver to ALL families throughout their area.

FINDING 10: (from data in Section 5)

Some parents were given little or no information at diagnosis, even those parents who had received the diagnosis in the last two years. Some would have liked another appointment soon after to discuss issues further.

Recommendation 4:

For each ELB and HSSB to consider their current practice concerning diagnostic assessment in relation to the guidance produced by the four Health and Social Services Boards in Northern Ireland (Four Board paper, 2003), the National Autism Plan for Children (NIASA, 2003) in England and SIGN in Scotland (SIGN, 2006) and to determine how waiting times might be reduced, how good information can be provided to parents and to arrange follow-up consultations so and that all families, wherever they live, have a consistent and good quality service.

3.5 Support for Families

FINDING 11: (from the literature and data in Section 5)

In this Review and in other research, parents and families rarely receive enough day-to-day support in living with children and young people with AS who can be very challenging and demanding. Many parents would like another pair of hands to allow their child to engage in an activity outside the home or to help in enabling parents to access activities and holidays as a family. A few families in the Review had been offered befrienders or money for holidays and these had been highly rated and appreciated, but were often 'one-off' or short-lived.

Recommendation 5:

For statutory and voluntary agencies to create mechanisms to evaluate the accessibility and take-up of services by families to ensure those that require services receive these and that resources are allocated effectively and fairly.

Recommendation 6:

For social services to work together with the voluntary sector and education to establish more provision and schemes to support parents and families in activities out of school hours during evenings, weekends and holiday periods.

3.6 Emotional needs of parents/carers

FINDING 12: (from the literature and data in Section 5)

Being a parent/carer of a child or young person with AS and dealing with their day-to-day lives at home within the family and also working with school staff is often very stressful and exhausting. In addition, parents (particularly the mothers) may have other painful issues and emotions to manage in relation to the rest of the family. Some mothers mentioned the problems arising when their partner did not want to accept the diagnosis and so did not really join with her in supporting their child. Others mentioned the guilt they felt towards their other children who were often 'short-changed' in terms of attention and family activities that were possible. Parent

support groups do go some way towards addressing these issues, but putting these topics more explicitly on the agenda might be helpful.

Recommendation 7:

That professionals and the voluntary sector consider how they might address some of the other needs that parents have in relation to themselves and other family members.

3.7 Multi-agency collaboration

FINDING 13: (from the literature and data in Sections 5, 7 and 8)

Many professionals and voluntary agencies may be involved with a child or young person with AS and their family, and the potential for conflicting advice, repetition of assessments and confusion is obvious. Multi-agency coordination is therefore vital. Some form of key-working system for families where many professionals are involved needs to be explored by services and with the family.

Recommendation 8:

For all those involved with a child or young person with Asperger syndrome and with their family to consider the roles and knowledge of others and to endeavour to present a coherent and streamlined programme of assessment and intervention to the family.

Recommendation 9:

For those working in education, social care, health and the voluntary sector to consider ways of informing other professionals and members of the public about Asperger syndrome so that others can understand their perspective and behaviour.

3.8 Numbers of children and young people with AS identified

FINDING 14: (from the literature and data 3.2.1)

The numbers of children and young people with AS have increased five fold in all 5 ELBs since 1999 from an average of 6/10,000 in 1999 to an average of 30/10,000 in 2005. This is in line with increased rates of identification in other parts of the UK. There is variation in the rates between the 5 ELBs (from 18/10,000 to 40/10,000) so there may be instances of over-identification and missed diagnoses.

Recommendation 10:

That the variation in diagnostic rates between the 5 ELBs is explored and that diagnostic practice is standardized, as far as possible, following published guidance (e.g. NIASA, 2003; SIGN, 2006) to ensure that resources are allocated appropriately and fairly by the Department of Education and the Health and Social Services Boards.

3.9 Numbers of children and young people with AS in primary and post-primary schools

FINDING 15: (from the data 3.2.2)

When the differences in school populations in the primary and post-primary phases of education in Northern Ireland are taken into account, there are proportionately more children identified in the primary sector with AS than in the post-primary sector. This reflects the increased awareness and diagnosis of pupils with AS and autism in recent years whereby more children are being diagnosed and diagnosis is occurring at a younger age. These data have significant implications for secondary schools in the future as there will be many more children with AS on roll than is the case currently, with identified needs requiring support.

Recommendation 11:

That the 5 ELBs consider how the post-primary schools will manage and meet the needs of the increasing number of pupils with Asperger syndrome in the future,

referred to as the 'autism wave' in the Task Group Report on Autism in 2002, in terms of resources and training.

3.10 Resources on ASD for teaching staff

FINDING 16: (from the literature and data in Section 6)

The Department of Education (2003, 2005), the 5 ELBs and Autism NI have all recently produced some excellent resources and training materials for teaching staff and other professionals following recommendations from earlier reports. These are very helpful in increasing the awareness of AS and giving ideas on how best to support these children and young people. Many staff in mainstream schools and other services are unfamiliar with Asperger syndrome. There are always questions about how others best learn in this situation, and providers of training in Northern Ireland and elsewhere need to have methods to evaluate their current training methods and to ascertain the impact of what they deliver.

Recommendation 12:

For those in all the statutory services and the voluntary sector to consider the resources and training available to professionals and parents, and evaluate how these are best delivered. As a matter of course, the Education and Training Inspectorate (ETI) reviews the use of ASD materials produced by the Department of Education during school inspections.

3.11 Role of the voluntary sector

FINDING 17: (from data in Section 8)

It is clear from this Review that there is an important role for the voluntary sector in highlighting needs and working with statutory agencies to consider how best to address these.

Autism NI, in particular, has been a pioneer in lobbying for, and developing, specific support for individuals with ASD and their families. The work by those in the voluntary

and independent sectors both complements and adds to what the statutory services can do.

Recommendation 13:

Those in the voluntary sector and the statutory services need to continue to work together and liaise to ensure that what they offer is congruent and avoids repetition and confusion for families. Each needs to decide in which areas they are best qualified and able to address and to share their development plans and goals, be it training, resources on ASD or support groups, for example. Two of their 'products' most valued by parents are the support groups and the befriending schemes for themselves and for their children, and these could be expanded to increase in frequency and to reach more families.

3.12 Interventions for children and young people with Asperger syndrome

FINDING 18: (from the literature)

Most children and young people with AS will need a number of different interventions to address their needs, not just one. A single intervention is unlikely to suit or be appropriate to ALL children and young people with AS or ASD (Jones, 2006; Jones & Jordan, 2006). Schools and parents will therefore require information and resources on a number of interventions and to have a means of assessing which may be helpful. There is a wealth of literature and an increasing number of videos and DVDs to illustrate different interventions. The Further Reading list at the end of the Review gives references to many of these.

Recommendation 14:

Parents and schools need guidance on how best to assess the needs of children and young people with Asperger syndrome, and then to make sensible decisions on which interventions (in the broadest sense of the term) to use. Understanding the principles of the interventions is the key, rather than using interventions without sufficient training. This is compatible with the policy of the Department of Education that the approach should be child-centred and not method-centred.

3.13 Data from the Parents

FINDING 19: (from data in Section 5)

A total of 59 parents (16% of the estimated number of families in Northern Ireland with a child with AS aged 10 to 18 years) returned a questionnaire. Over half of these parents were satisfied with their child's current school or college placement and said this was their greatest source of support. That said, some had had very difficult experiences with previous schools, their comments suggesting that the staff had misunderstood the child's behaviour or had not wanted 'challenging children' in the school.

Some parents felt unsupported after diagnosis; others felt supported in the early years, but then support seemed to disappear. They were asked to rate overall how they felt 'today' about the support they were receiving using a scale from 1 (very dissatisfied) to 10 (very satisfied). Twenty-three parents (41%) said they were very dissatisfied, giving a rating of 1, and only 6 (11%) gave the highest rating of 10, two of these citing Asperger's Network as their main support while the third parent said the private psychologist had been the most supportive.

The nature of AS is such that parents are almost constantly under pressure from their child and the requests of others involved. They have to support their child outside the home and liaise with professionals who may or may not agree with what is being requested or may or who may not have the resources. Within the home and family, parents have to attempt to share their time equally with other children and their partners. It is therefore not surprising that these ratings are so low. The statutory agencies and voluntary organisations have worked very hard to enhance and improve services in recent years in Northern Ireland and there is much to be commended. The extent of need is often great, however, and there are many ways in which services could support families more than they do currently. It is not always a matter of more funding. Some parents commented that the options which were offered (which were expensive) were not always what they wanted.

Recommendation 15:

A key question for all providers to ask parents is ‘What would make a difference to you and the family at this point?’, as opposed to only offering what exists within an area (e.g. ‘We have a group/a workshop/a befriender/...’).

3.14 Responses from staff in schools and colleges

FINDING 20: (from data in Section 6)

Overall, the tone of the replies was very positive and almost ALL schools which had children with AS could point to improvements over the last 3 years both in terms of what they were able to do, and in their understanding of the condition. This appeared to be the case across the 5 ELBs.

The key areas that staff identified which had improved were:

- Knowledge and awareness of AS and its implications for the child and the parents;
- Opportunities and availability of training both in school and externally;
- Working much closer with parents and a desire to collaborate more;
- The value of autism advisory services – almost all said these were very useful and that they would like more; and
- The value of Classroom Assistant (CA) time.

3.15 Life beyond school

FINDING 21: (from the literature and data in Sections 5 and 8)

Life after the school years is one of parents’ biggest concerns and, as yet, there are insufficient options and support available for young people with AS both in Northern Ireland and the rest of the UK. There are some examples of good projects, but these, as yet, only serve a small proportion of those with AS. Key areas to consider are the support needed to decide on a feasible career, to enter and succeed in Further or Higher Education and then to gain and maintain employment.

There are now better assessment services in place in Further Education (FE) and Higher Education (HE), and reasonable financial support available to provide support (e.g. the Disabled Student Allowance), if the student is willing to disclose their diagnosis (Martin, 2006). Many adults with AS will then need to be supported in finding a job and in keeping that job in its early stages. There are some very successful schemes in one or two areas of the UK, but these need to be multiplied to meet the need of all those with AS in need of support. A pilot supported employment scheme has started in Greater Belfast (Employment For Autism (EFA)), and when this is established and working well it would be excellent to extend this in terms of numbers and areas of Northern Ireland covered. If not, the reality may be that the young person with AS, having achieved well at school, may remain at home unemployed and on benefits after leaving formal education. This has serious consequences for all concerned – the young person, the family and society as a whole.

Recommendation 16:

That young people with AS are given much more support than they appear to receive currently to help them choose a suitable route after school, to obtain support in Further and Higher Education and to find and keep employment At the moment in the UK, this task often falls to the voluntary sector, but those working in schools, in FE and HE should examine their policy in practice in this area and work with statutory agencies to enhance current provision.

3.16 Views of children and young people with Asperger syndrome

In considering these findings, it is important to acknowledge individual differences and needs within this population. That said, common concerns were their awareness of the difficulties they had in understanding and relating to other children. Linked to this was the bullying and teasing they experienced at school. A significant issue was the feeling that others did not understand them and recognise their needs. One respondent suggested that teaching staff should ‘*try living in their world*’. Positive comments were made by some about having Asperger syndrome and the support they received, but the over-riding impression given was that life was hard and people

did not make sufficient adjustments to enable them to manage and enjoy school and life generally.

3.17 Issues around giving the diagnosis of Asperger syndrome

FINDING 22: (from the literature)

For any child or young person, it is important to consider the pros and cons of making and sharing the diagnosis. There is sometimes no clear-cut route to take, and parents, staff and the child or young person might not reach a consensus on this. Some of the advantages and disadvantages are discussed in a recent book edited by Dinah Murray (2006), which is an excellent resource for young people, parents and professionals alike.

Recommendation 17:

That professionals are mindful of the dilemmas and issues in giving the diagnosis of Asperger syndrome to a child or young person, and in deciding whether to disclose this to peers, teaching staff and to future employers. There is a need to enable parents and the child or young person to arrive at the most appropriate course of action at any given time.

3.18 Maximising skills and interests

FINDING 23: (from data in Section 4)

Comments from the children and young people with AS in this Review illustrated very well how hard their lives are and how other people can make them feel good about their achievements or how they can be extremely critical leading to feelings of worthlessness and anger.

Recommendation 18:

All those involved with a child or young person with Asperger syndrome need to identify that individual's skills and strengths, and find ways of recording and highlighting these to raise their self esteem and status in the eyes of others.

3.19 Teasing and bullying

FINDING 24: (from the data in Section 4)

Teasing and bullying were the most often cited negative reactions to the condition reported by the children and young people in this Review, and require urgent attention and action.

Recommendation 19:

That staff in schools and colleges are made very aware of the high probability of bullying and teasing, and that they identify crisis times within the school day and areas of the school where this is most likely to occur.

3.20 Insight into Asperger Syndrome

FINDING 25: (from the data in Section 4)

Overall, the comments made by the children and young people with AS showed they had a fairly accurate picture of how the condition affected their perspective and behaviour. In addition to the negative comments, some did have high expectations for future careers and did enjoy some aspects of their lives at school and home. Some parents said their child had enjoyed meeting others with Asperger syndrome at support and social groups as it was a relief to know they were not alone and for some, they shared the same interests.

Recommendation 21:

It is only relatively recently that attention has turned to sharing the diagnosis and discussing this with the individual with Asperger syndrome (Murray, 2006). Many adults have written about the huge benefits they have had from meeting others with AS. Both these interventions need careful consideration as they are not automatically perceived by the young person as a good or positive thing. What is important is that the two topics are on the agenda for discussion with parents, professionals and the young person him or herself so that the child or young person does not lose out.

SECTION 1: INTRODUCTION TO THE REVIEW

1.1 Aims of the Review

The two key aims of this Review were:

- To identify the needs of young people with Asperger syndrome who are aged between 10 and 18 years and living in Northern Ireland; and
- To identify what services are currently provided for these young people and their families and how these might be further enhanced.

1.2 Purpose of this Review

The purpose of this Review is to provide information which can be used as a resource for all those working and living with children and young people with Asperger syndrome. It will:

- Provide data on the numbers of children and young people with AS living in Northern Ireland and the implications of this;
- Give information and comments from young people with AS on their experiences and views of services;
- Describe the views of parents of children and young people with AS on their experiences;
- Disseminate ideas from professionals and voluntary organisations on good practice and what needs to happen to enhance services;
- Provide references to the literature and other resources on AS for children and young people with AS, and for parents and professionals; and

- Reference and comment on other reviews, national guidance and policy documents on AS produced in Northern Ireland and in other countries within the UK.

1. 3 Background to the Review

The principal aim of NICCY is to:

'...safeguard and promote the rights and best interests of children and young persons' and 'keep under review the adequacy and effectiveness of law and practice relating to the rights and welfare of children and young persons'.

All this is done with explicit reference to the UN Convention on the Rights of the Child, ratified by the UK Government in 1991.

The needs of children and young people with autistic spectrum disorders (ASD) have been brought to the attention of NICCY from a number of different sources. They were raised as a pertinent issue in both Kilkelly et al's (2004) research on children's rights within Northern Ireland and the subsequent SHOUT consultation. The Task Group Report on Autism in Northern Ireland (2002) also highlighted the needs of these individuals, commenting that:

'Within the last few years educational, health and social services provision for children and young people has entered a period of rapid improvement in many areas of Northern Ireland. However, parents, voluntary bodies and statutory bodies alike recognised that there is still much progress to be made before it will be possible to say that all children and young people with ASD are being identified and that their needs are being fully met' (Task Group Report, 2002: ii).

There have also been 87 referrals to the Legal and Complaints Department at NICCY relating to provision for children and young people with ASD.

1.4 Main Objectives of the Review

The main objectives of the Review are as follows:

- (a)** To produce a comprehensive Literature Review covering the following topics:
- Definition of ASD and Asperger syndrome;
 - The likely numbers of individuals with Asperger syndrome within Northern Ireland;
 - The needs of individuals with Asperger syndrome and their families/carers;
 - Relevant policies in Northern Ireland;
 - Existing research on Asperger syndrome within Northern Ireland, and elsewhere;
 - Issues affecting individuals with Asperger syndrome and their families;
 - Examples of good practice across Northern Ireland; and
 - Examples of good practice elsewhere, both in terms of policy and practice.
- (b)** To provide a comprehensive overview of existing services and provision for individuals with Asperger syndrome in Northern Ireland.
- (c)** To identify gaps in service provision for individuals with Asperger syndrome in Northern Ireland.
- (d)** To identify examples of good practice.
- (e)** To ascertain if regional differences exist with regard to diagnosis and provision for individuals with Asperger syndrome in Northern Ireland.

(f) To ascertain the views of children, parents/carers and relevant professionals regarding:

- The diagnostic process;
- The effectiveness and appropriateness of existing services;
- The extent and nature of unmet need; and
- Desired developments within the field.

(g) To evaluate the appropriateness of existing (and planned) policies, and to determine the extent to which desired policy outcomes are being fulfilled.

(h) To ascertain to what extent inter-agency working is taking place and is effective within these areas.

(i) To offer evidence-based recommendations for the future development of both policy and practice.

1.5 Methods of data collection

During the period January to June 2006:

- A Literature Review was undertaken on current literature and research relating to Asperger syndrome and on policy, legislation and guidance in Northern Ireland.
- Questionnaires were devised and circulated to:
 - Children and young people with Asperger syndrome;
 - Parents/carers of children and young people with Asperger syndrome;
 - Mainstream and special schools and colleges; and

- Providers of services.
- Interviews were held face-to-face or by telephone with parents, health professionals, social workers and children and young people with AS.
- Data which had been collected by the Department of Education in Northern Ireland on the numbers of pupils with Asperger syndrome were analysed.

SECTION 2: LITERATURE REVIEW ON ASPERGER SYNDROME

The topics covered in this Literature Review include:

- Definitions and diagnosis of Asperger syndrome;
- The prevalence of Asperger syndrome and numbers of children and young people with AS living in Northern Ireland;
- Regional differences which may exist;
- Diagnosis, assessment and interventions in Asperger syndrome;
- Demands on parents and families with a child with AS;
- Multi-agency collaboration;
- Policy, guidance and reports on ASD in Northern Ireland;
- Role of the voluntary organizations in ASD;
- Forms of support for children and young people with Asperger syndrome and their families out of school hours;
- Life beyond school;
- Staff training needs in Asperger syndrome; and
- Support for families with a child or young person with Asperger syndrome.

2.1 Diagnosis and definitions of Asperger syndrome

2.1.1 Autism spectrum disorder and Asperger syndrome

Autism spectrum disorder (ASD) is the umbrella term for a range of conditions that have a common core of difficulties identified as 'autistic' and roughly corresponds to the category of *Pervasive Developmental Disorders*. Kanner (1943) was the first to identify *autism* as a separate and distinct condition. Although he described children who were mute and showed poor adaptive functioning, his original impression was that all were fundamentally intelligent, assuming that what he called their 'islets of ability' were in fact true representations of their general level of ability and that it was the autism that was somehow 'masking' their innate capacity. It was left to Wing and her colleagues (Wing & Gould, 1979) to demonstrate, in a large population study, that autism could (and often did) co-occur with severe learning difficulties. Wing (1981) also introduced the work of Asperger (1944: translated, Frith, 1991) to the English-speaking world and with it, the recognition of a far more intellectually- and linguistically-able group who nevertheless shared a common 'triad of impairments' (see below) with others within an 'autistic spectrum of disorders' (ASD). The 4th edition of DSM (DSM-IV: APA, 1994) and the 10th edition of ICD (ICD-10: WHO, 1993) introduced the category of 'Asperger Syndrome/Disorder'. Both these systems also recognized a larger group of individuals who do not meet the criteria for autism but who also share a common core of difficulties. These were categorised as '*atypical autism*' or '*pervasive developmental disorders not otherwise specified*'.

Autism spectrum disorder (ASD) covers the three main categories of:

- Autism (autistic disorder);
- Asperger syndrome (disorder); and
- 'Pervasive developmental disorder, not otherwise specified (PDD-NOS; atypical autism).

Wing (1996), who first conceptualized the term, included a broader range of conditions but these three are the most widely accepted. The diagnostic systems have a hierarchical system of classification such that, if someone meets the criteria

for autism, for example, they cannot then be said to have Asperger syndrome or PDD-NOS, but not all diagnosticians follow these guidelines.

Debate and discussion continues on the existence and the distinctions between different subgroups under the heading of autism spectrum disorders and these are not always clear-cut (Bishop, 1989). In addition, deciding where the cut-off point might be between 'typical development' and an ASD is challenging.

Only recently, research has focused on differentiating categories at the 'borderlands' of autism (Barrett et al., 2004), that is, the point where individuals might be distinguished from individuals with language disorders or non-pathological variations of human development – the 'eccentric and unusual'. It is not sufficient that individuals have unique or unusual learning and thinking styles in order to attract a diagnosis; their differences must be such that they significantly interfere with functioning in their everyday lives.

2.1.2 Diagnosis of Asperger syndrome

There are two major diagnostic classification systems in use. One is the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) and the other is the International Classification of Diseases, Version 10 (ICD-10), which is the most often used in the UK. Each has similar criteria for the diagnosis of autism based on the triad of impairments (see **Appendix 1**), where the behaviours are discrepant from the mental age of the individual. These criteria have changed over the years and will continue to change as understanding of the condition develops.

For a diagnosis of Asperger syndrome, there should have been no significant delay in the development of speech and the child should not be intellectually impaired. The individual should be within the average, or above average, range of intelligence. Those involved in diagnostic assessment do not always strictly follow these criteria and so there are some children who have had delayed speech and language and who are below average intellectual ability who have been diagnosed as having Asperger syndrome. Some cognitively-able children do not develop speech at the usual time but become fluent speakers later on. Some diagnostic teams would then diagnose these children as having high functioning autism (HFA), whereas others

might argue that the child has Asperger syndrome. It is possible then for a child's diagnosis to be changed with age by the same diagnostic team or to be given different diagnostic labels depending on who makes the diagnosis. This can cause distress and confusion to parents and professionals alike, and needs to be explained. It also appears to be the case for some children that they are considered to have Asperger syndrome if they attend mainstream school, irrespective of their clinical history or behaviour. Defining children with ASD by educational setting is not good practice.

Some children with AS attend schools for children with learning disabilities, even though they are not intellectually impaired, because the school building and class sizes are smaller and more staff are likely to have knowledge of ASD. In England, a number of independent schools have been established solely for pupils with Asperger syndrome, where mainstream schools have not been able to meet their needs. There are also some children with AS for whom school has been so difficult that education is provided on an individual basis by tutors working outside of school premises who focus on their strengths and interests and help to build self esteem.

The only defined differences between AS and autism are that there should be no significant general learning difficulties and no significant delays in language acquisition. However, the way in which the core difficulties (the triad of impairments) are manifested may also differ. Those with AS, as distinct from autism, are often said to be sociable (just lacking the skills and understanding to interact successfully with others), to talk *at* rather than *with* others, to be clumsy (although there is not good evidence that motor problems are confined to those with AS), and to show their inflexibility through the establishment of rigid interests and routines, often complex in nature. Although AS exists as a separate category in both diagnostic systems, only now are more reliable and valid diagnostic tools being developed such as those which are already well accepted for autism.

Different authors have characterised AS in different ways which, in turn, has led to great disparity in the way it is diagnosed, with pragmatic factors often having an influence (choosing a label to fit available provision, or conversely, choosing a label that is judged more acceptable to parents or to an individual). There has been a

plethora of studies seeking to find systematic differences between AS and what is termed 'high functioning autism' (HFA: where the person meets criteria for autism and where their language was delayed, but currently has no general cognitive or structural language difficulties). The consensus is that such a distinction cannot be made (Prior, 2003), and many authors and working parties have agreed that services should work with the broader concept of ASD and then look to individual differences within that frame (DfES, 2002; NIASA, 2003; Jordan, 2005b). However, there may be social or political reasons why the label of Asperger syndrome is preferred; this may be related to self-esteem in individuals with AS or the fact that it may be more easily accepted by parents.

2.1.3 Misdiagnosis and missed diagnosis in Asperger syndrome

Agreeing on and confirming the diagnosis of Asperger syndrome is not always an easy process and it is possible for misdiagnosis to occur because there is no definitive medical, biological or psychological test that can confirm the diagnosis of Asperger syndrome. Diagnosis is made on the basis of the behaviours observed and reported by parents and others. It is therefore subjective and dependent on the personal opinions and skills of the different professionals who see the child or adult. There are agreed lists of criteria for Asperger syndrome (see **Appendix 1**) which diagnosticians need to use as a guide and on which diagnostic instruments are based, but it can be hard to reach a consensus of opinion on whether a child or adult meets some of these, as they are based on behaviours seen.

So, it is possible for the following scenarios to occur:

- A child or adult with Asperger syndrome is incorrectly diagnosed as having autism and additional learning disabilities;
- A child or adult with autism and learning disabilities might be incorrectly diagnosed as having Asperger syndrome; or
- A child or adult with Asperger syndrome may not be diagnosed as such and may be misdiagnosed as having a mental illness, an emotional or behavioural disorder or be viewed by others as deliberately naughty, lazy or difficult.

2.2 Disability or Diffability?

As with other disability areas, there is a group of individuals with ASD who challenge the medical characterisation of ASD as a 'disease' in need of a 'cure' (Dawson, 2004; Prince-Hughes, 2002; Sainsbury, 2000; Sperry, 1998). Wendy Lawson, a very able woman with Asperger syndrome, prefers the term 'diffability' to disability. 'Diffability' suggests that we are all differently-abled, and she and others argue that there are advantages as well as disadvantages to having Asperger syndrome. She and others argue that professionals and schools should not focus on trying to make children with AS change to become like a typical child, as in many respects this is not possible for the child with AS to achieve. In addition, we will lose out if we fail to appreciate and capitalize on the particular skills, knowledge, honesty and perspective of a child with AS, a failure which can reduce the child's feelings of self-worth.

The evidence of a high genetic link and a broader phenotype within families of individuals with ASD (Le Couteur, 1996) has led some researchers to make the case for the evolutionary advantage of some traits associated with ASD (Baron-Cohen, 1995; Baron-Cohen et al., 1997; Wheelwright & Baron-Cohen, 2001). Baron-Cohen (2004) adopts Asperger's characterisation of autism as an extreme form of maleness and argues that these different strengths and weaknesses comprise different ways of understanding and acting on the world: 'systemizers' (mostly male) who process information naturally in terms of physical systems, and 'empathizers' (mostly female) who process information in relation to its social and emotional characteristics. These views are speculative but emphasise the point that differences cannot automatically be equated with deficits. There is a preponderance of males over females with the condition, as there is in many developmental disorders. The overall figures are given as one female for every four males, but the ratio changes with ability level. For those with severe learning difficulties and other problems, there may be almost equal numbers of the condition, but for those with AS, the ratio may be between nine to fourteen males to one female. Some have suggested that the diagnostic systems are biased towards recognising males, and that female Asperger syndrome, for example, remains to be delineated and that girls with AS might be missed and/or seen instead as a child or young person with an emotional and behavioural difficulty. However,

there is as yet no evidence to support this contention.

2.3 Differences within the population of individuals with Asperger syndrome

Individuals with AS are very different from one another, perhaps even more so than the typical population, since their difficulties in learning through social means result in their exclusion (at least partly) from a shared cultural view of the world; they have to try to make sense of the world for themselves, and each individual with AS will have his/her own perspective. The severity of their AS will also vary, and they will have different levels of general intelligence, language ability and other characteristics. There is nothing that protects children or adults with AS from having additional problems, and some other conditions are more common in AS than in the general population (see Sections 2.6 and 2.8). Just as with other individuals, they will also each have their own personality.

In spite of differences between individuals with AS, they share a common core of difficulties that define those with ASD and differentiate them from other conditions. This commonality lies in a core set of developmental differences from the typical that were first identified by Wing (1988) and have come to be known as the '*triad of impairments*'. Different versions of this exist but an accepted version (Jordan, 1999) identifies difficulties in:

- *Social and emotional* understanding;
- All aspects of *Communication*; and
- *Flexibility* in thinking and behaviour.

Note that these are not behaviours as such, since there is no such thing as an 'autistic' behaviour; they are areas of development. The diagnostic criteria will give examples of behaviour typifying each difficulty, but there will be different behaviours resulting from these difficulties according to other characteristics of the individual (e.g. personality, level of intelligence, language ability, sociability, age), their experience, and the situation they are in.

The three categories within ASD define medical categories because that is the system in which they occur. However, the reality is that there is no clear cut-off point in terms of a qualitative difference between those with and without an ASD; the dimensions of the 'triad of impairments' (above) are just that – dimensions of human variability. Thus there may be individuals who are extremely lacking in social and emotional empathy, have extremely poor communication skills and who are extremely inflexible in their thinking and behaviour, yet who function well in society (perhaps as a computer engineer in a research laboratory) and do not require special support to do so (perhaps because of a particularly supportive environment). There is no point in pathologising such individuals, although we should be aware of some key issues:

- An individual whose differences are not understood or tolerated may be 'pushed' into failure to function and thus into meeting criteria for an ASD;
- Conversely, providing an 'ASD-friendly' environment (at school, for example) will enable more individuals to function without special support;
- Those more severely affected are liable to require help and support throughout the lifespan, even when the individual has acquired many skills and perhaps holds down a job and maintains a family; the person remains vulnerable to the effects of stress;
- Different 'stakeholders' (parents, professionals, researchers, proponents of particular approaches, individuals with ASD themselves) will have different views on the nature and value of the diagnostic labels (Jordan, 2005a); and
- Diagnosis may be a way of helping others (parents, teachers) understand the child and work more effectively with him/her, or it may help the adult or young person understand, and come to terms with, him/herself. It may not, on the other hand, be the best way to ration or 'gate-keep' resources (Volkmar, 1998; NIASA, 2003).

In the UK, an assessment of special needs is recommended as the basis for providing services (Department for Education & Skills, 2002; NIASA, 2003), but Jordan (2005b) argues that, although education has to be based on the assessment of individual needs, in ASD the medical category (in its broadest terms) is necessary as a way of identifying and highlighting those needs to professionals and parents alike. In other words, we cannot rely on our normal intuitive understanding of behaviour when dealing with ASD; we have to view the behaviour through the 'lens' of understanding as it arises in the context of the ASD (Cumine et al., 1997). It would be difficult for most professionals who are not familiar with ASD to quickly (if at all) draw the right conclusions about the behaviour seen in a child with AS or ASD, if they did not know the child's diagnosis. Thus the child might be viewed instead as naughty, deliberately challenging, or introverted and so not be given appropriate interventions. Making and sharing the diagnosis for children with AS who experience significant problems at school or in daily living is therefore very important if they are to receive effective and sensitive support.

2.4 Asperger syndrome does not mean the child or adult is mildly affected

In many texts, there are misleading statements to the effect that individuals with AS have a 'mild form of autism'. This opinion has been given on the basis that children and adults with AS are of average or above intelligence and have good speech and language skills. But it is not necessarily the case that the nature of their difficulties is mild. It is true that those with greater cognitive ability and with good language skills are more able to acquire skills, including the social and communicative skills that others learn naturally, but which those with an ASD have to 'work out'. Thus, over time, they may develop more adaptive ways of behaving and may overcome, or at least mask, the problems that stem from the triad of impairments. However, underneath, and from the perspective of the person with AS, their difficulties may remain as strong as ever, so it is misleading (and potentially harmful in that it may deny support) to refer to their condition as 'mild autism'.

Research is also beginning to supply evidence that the category of Asperger syndrome is often misunderstood or inconsistently applied, and may be used to deny

services (Hart & Geldhart, 2001; Preece & Jordan, in press) in the belief that such individuals and their families have less need for support than individuals with other ASDs.

2.5 Asperger syndrome in the years 10 to 18

In the early years, because there are no general delays in development, the signs of AS may be more subtle and difficult to detect than classic autism. In particular, the often prolific speech of those with AS may mislead people into assuming that any difficulties are the result of 'deliberate' action, and the child may be characterised as having a behavioural difficulty rather than a disorder of understanding and operating in the social world. This means that diagnosis is often extremely delayed (Howlin & Moore, 1997) and may not happen until adolescence. Thus, in the years from 10 to 18, many children with AS may remain without a diagnosis or may be newly-diagnosed and just coming to terms with the implications of that. They and their families may also have experienced years of frustration in trying to understand and get their needs accepted, and their experience of school may be far from successful or happy (Gerland, 1999; L. Jackson, 2002; Lawson, 2003; Sainsbury, 2000).

These years are challenging for most young people, but the 'normal' difficulties of adolescence are exacerbated in AS by difficulties in understanding themselves or others, problems in gaining and maintaining friendships for support, unusual and potentially isolating and obsessional interests, and difficulties in communicating effectively to make their needs known and to get their needs met. With adolescence, emotional lability is likely to increase and young people may find it hard to understand and recognise their emotional states, even if they could before. They may show wild swings of mood and need help to relax and develop calming activities. In addition their peers will also have their own issues at this time and that makes avenues of support, such as Circles of Friends and buddy systems (Whitaker et al., 1998) harder to establish, if they have not happened earlier. Students with AS may also at this time begin to be aware of their differences from others and, depending on their personality and general aspirations, may feel themselves to be 'failures' and become depressed.

They may also (but not always) react badly to the labelling that follows a diagnosis and resent being 'singled out' by the measures (such as in-class support) provided to help with inclusion in mainstream settings. At the same time, the experience of secondary school is far more subject-centred, rather than child-centred, while the school is likely to be larger than primary school and involve more frequent and difficult transitions from class to class. There will also be more occasions when pupils are not being supervised by adults and when bullying is more likely to occur.

2.6 Co-morbid diagnoses and Asperger syndrome

There are some conditions that are often associated with ASD (Tantam, 2003). Some of these, such as late-onset epilepsy, are common within ASD, but less so in those with AS. Some, such as general severe cognitive impairment and specific language impairment cannot, by definition, occur in AS, whereas they are common in autism (Reitzel & Szatmari, 2003). Some, such as sensory abnormalities, are so common in both ASD and AS that they are often regarded as an expected characteristic of all ASD, and even a potential fundamental cause of other characteristics such as social withdrawal (Bogdashina, 2002). Other conditions (e.g. language disorders, dyslexia, dyspraxia) appear to have some genetic link to ASD in that they are common, not just in those with ASD but also in their close relatives. Finally, there are conditions (such as Attention Deficit Hyperactivity Disorder (ADHD)) that exist in their own right without an ASD, but also form part of the behaviour pattern associated with ASD.

2.7 Sensory Sensitivity

Unusual or heightened responsiveness to general sensory stimulation is common, if not universal, in ASD. It is not certain whether it is a core problem that then leads to secondary problems in perception (i.e. making sense of the world: Bogdashina, 2002), or whether the fundamental problem is in categorising and perception, with sensory problems a secondary consequence of thus needing to respond to too much detail (Happe, 1994). What is clear is that sensory problems have a profound effect in determining which learning environments will be the most conducive to learning.

Autobiographical accounts of ASD often highlight sensory abnormalities as a prime feature of the condition (e.g. Grandin, 1995; Joliffe, Lansdown & Robinson, 1992; Williams, 1996).

Synaesthesia, where senses become muddled and, for example, words or numbers may appear as colours, is also far more common in ASD than in other groups. At a treatment level, sensory integration therapy is becoming more established (Berger, 2001), and sensory rooms are a common feature of specialist schools for children with ASD in spite of the lack of evidence of their effectiveness (Stephenson, 2002). Their use with children with AS is less well established, since they are not generally accessible in mainstream settings, especially at secondary level. Some individuals with AS or HFA endorse treatments such as coloured lenses and auditory integration, although there is as yet no scientific support. Some classroom adaptations for 'low arousal' are detailed below.

2.8 Additional Conditions

ASD may occur in combination with almost any other condition, although it is often very difficult to obtain a second diagnosis once it has been established that there is an ASD. The actual label may not be important, but it is important that everyone (including, where possible, the child him/herself) understands all the conditions that may be affecting the child and interacting with the ASD (as with severe learning difficulties: Jordan, 2001, or visual impairment: Jordan, 2004). Classic forms of autism invariably have an associated language disorder (although not diagnosable as such: Reitzel & Szatmari, 2003), and AS may have dyslexia associated with it as well as degrees of motor clumsiness, which in some cases result from associated dyspraxia. All ASD conditions are characterised by attention deficits and hyperactivity is common, so ADHD may also be considered (unofficially) as an associated condition, at least in some cases. Conditions like Tourette's syndrome (which is also more common in ASD than in the general population) can be missed, and the symptoms (sudden movements or speech that appear beyond the conscious control of the person) attributed to the difficulties in impulse control and lack of social awareness that are seen in ASD. Some treatments, such as relaxation techniques, may help both conditions, but there may be specific treatments for conditions that the

individuals could benefit from, whether or not they have an ASD. It also helps for the teacher and other pupils to understand if, for example, sudden outbursts of swearing can be seen as stemming from Tourette's syndrome and not from challenging behaviour.

2.8.1 Anxiety

Anxiety is another common, if not universal, accompaniment of ASD. Anxiety levels will vary according to the child and the circumstances but, as the child moves into adolescence, anxiety almost invariably increases. For many children with ASD, the levels of anxiety are so high that they lead to actual additional disorders of high anxiety. One such disorder is that of obsessive-compulsive disorder (OCD), which, as in other cases, will need to be treated. Problems arise where the existence of the secondary condition is not recognized and the symptoms are confused with the obsessional behaviour that is part of ASD. One informal guide (as a precursor to seeking medical help) to the difference is whether or not the individuals appear to gain satisfaction and a reduction of anxiety from the performance of the 'obsessional' activity (suggesting it is part of the ASD), or whether performance just leads to continued and even increasing anxiety, so that it has a 'driven' quality (suggesting it may be an OCD). Treatments that are based on cognitive behavioural therapy (CBT) are usually the most effective for all anxiety disorders in ASD (especially in AS, where language makes such therapy more accessible), but in most parts of the UK, there are not enough trained personnel to deliver this therapy. Thus, more general approaches, based on the same principles, can be used by teachers and support workers and have a beneficial effect, especially if used in the early stages before the anxiety has become too chronic or severe (Sofronoff & Attwood, 2003). What is important is that the interaction with ASD is noted, but that treatment is for the anxiety disorder in its own right, rather than trying to tackle the ASD, because that approach will be too long-term to be effective.

2.8.2 Phobias

Phobias are also a common anxiety-related disorder in AS. The problem with phobias is that people avoid the situation of their fear (true of all of us, as well as those with ASD), and so the phobia never gets better because there is no opportunity to desensitize the fear. Recognising the fear can be a first step but this may be a

problem in ASD where there is little conscious awareness of emotions when the child is young. Helping children with AS become aware of their own emotions (before trying to teach them to recognize facial expressions of those emotions in others) will prevent them reacting in panic and distress, and enable taught strategies for coping to be put in place. Even better is to teach the child with an ASD (easier in those with AS, with good language and cognitive ability) to recognize the first signs of fear in themselves, and to then have an activity to reduce that anxiety or fear (closing eyes and humming, perhaps) before it erupts in difficult behaviour. Giving a child a strategy that enables them to tolerate some exposure to the feared stimulus may be the first step in helping them overcome their phobia. Of course, most people have phobias and these can be tolerated as part of life, but the danger in ASD is that they may develop phobias of things that are difficult to avoid (like hand driers) so they may need to learn to cope with the phobia and try to reduce it if it is not to limit their quality of life. Often understanding the stimulus (e.g. how the hand drier works and the time lag before the fan switches off) can help reduce the anxiety, and visual 'plans of action' to deal with the anxiety will then have a better chance of working.

2.8.3 Depression

Depression is also a common mental health problem that often appears in adolescence in AS and may arise from exogenous factors such as the increasing realisation of difference and limitations on life opportunities or from inappropriate management and provision. Teaching staff may not be able to treat these medical conditions but they are in a good position to alert others when symptoms appear so that help can be sought, and to work with the children in helping them to develop a realistic appraisal of their problems and ways to tackle them. Programmes that help children develop a sense of self-esteem and which build on strengths, rather than emphasizing difficulties, can be effective general approaches to help depression.

Also, CBT approaches that focus on small solution-focused problem solving and that teaches individuals to 'self-reward', with patterns of disliked tasks being followed by favourite activities, will also help lift depression, at least in its early stages. However, just as for the typical population, depression can be a serious mental health problem and needs to be treated medically. The most effective methods often combine psychological and medical treatments, but it is not a good idea to dismiss the

symptoms of depression just because the person has an ASD. There is an increased risk of suicide in young people with AS and so depression should always be seen as a sign that extra help and support is needed, and not an inevitable consequence of ASD. Some individuals will develop bipolar disorder, where periods of depression alternate with periods of manic activity and an extreme emotional 'high'. Again, medical treatment should be sought and the earlier this is treated the better.

2.8.4 Schizophrenia

Since ASD does not protect against mental health conditions, schizophrenia can sometimes develop alongside an ASD. It is certainly not a common condition in ASD, but some symptoms (especially in chronic schizophrenia) may be similar to those found in ASD so, if the young person has not received a diagnosis in childhood, an adult psychiatrist (who may be more familiar with schizophrenia than with ASD) may wrongly attribute symptoms of AS to symptoms of the former. Lawson (1998) tells the not unfamiliar tale of being asked by her psychiatrist whether she 'heard voices' and replying in her literal way that naturally she did (thinking perhaps that it was a question about her capacity to hear). She then spent a long time misdiagnosed as having schizophrenia, on inappropriate medication, and unable to lead a productive life. She has managed to overcome these traumas, but not for many years, so it is important, when seeking help from medical professionals who may be unfamiliar with AS, to support the young person with AS with providing them with someone to act as a 'translator' for just such questions, even where the person has very good language skills.

2.9 Understanding and managing behaviour in Asperger syndrome

2.9.1 Understanding behaviour

All behaviour has meaning and serves some function. The problem in AS is that the meaning may differ from the typical case, so a parent, support staff or the teacher, for example, may misunderstand the meaning of the behaviour (or may attribute a meaning and intention which is not valid for the person with AS) and thus fail to respond in ways that support the individual. Understanding does not necessarily mean tolerating, of course; some behaviours are unacceptable and need to be

changed, and compromise and negotiation need to be taught. However, unless we really understand that behaviour, it will be extremely difficult to effect such changes and help the individual manage his/her own behaviour in a better way. Challenging behaviour, by definition, is behaviour that gets noticed and disturbs those around the individual, often affecting the quality of life of the individual, his/her family and teaching and support staff. Thus, it has high priority for intervention in AS, but that intervention must be rooted in understanding if it is to be successful. Challenging behaviour is not a characteristic of individuals (so an individual should not really be described as 'having' challenging behaviour except as a shorthand to mean they are exhibiting challenging behaviour in certain situations at certain times). It is a reaction between a person and a situation and so, to understand the behaviour, we not only need to understand the individual but the situation as well. Ewa Zarkowska at an autism conference in 2003, described challenging behaviour as a 'gift' because it alerts others to identify the message the individual is trying to convey, and to consider how they might teach the individual an alternative method of communication and modify their demands (or other factors) to prevent the behaviour in the future.

2.9.2 Understanding function

Understanding the function of the behaviour in any situation means using knowledge of the child or young person and the situation, and careful observation of what actually occurs in that situation. A good question to ask, that will guide the observation is '*What would the individual want to be communicating, if s/he could communicate?*' Children with AS will have speech, but that does not mean they will be able to use it to communicate. This is especially so when they are in a general state of anxiety or stress. It is common for individuals with AS to lose their ability to speak when highly distressed, and most will benefit from some visual way of expressing their immediate needs or frustrations. Examples are simple symbols that indicate they want to be left alone to calm down (red), or they would welcome some comfort through deep massage (yellow), or they want help in problem solving the situation (green). Function is very different to 'trigger'. It is helpful to know what stimuli or events might trigger anxiety or fear in an individual, but a general search for 'triggers' for each behaviour is generally not productive.

It has to be remembered that a single behaviour may serve more than one function. For example, a child may have some pain (e.g. toothache, constipation) which the child with AS may not be able to locate (body awareness is very poor and needs training) and may not understand how to communicate. What happens is that there is a directly triggered behavioural response – perhaps a form of self-injury such as head banging. The child may not be aware of his/her pain, but may notice that a consequence of head banging is that people express concern and try to meet his/her needs. When the child is head banging, no one makes further demands in terms of work or social contact, so the child learns that head banging is a good way of getting out of doing something they do not want to do. It is important to note that this is not deliberate, manipulative behaviour, but learned responses of which the child may not even be aware. When it comes to treatment, however, each one of these functions has to be tackled, so the child is taught in each case a different behaviour to serve each of the functions: a visual way of locating and communicating pain, a way of asking for a shared activity with others, and finally, a more acceptable way of indicating that the child does not want to do this work now.

2.9.3 Managing behaviour

This last issue raises difficulties in schools and colleges, where teachers, not unreasonably, feel that the child or young person with AS has to learn to conform to curricular demands and cannot pick and choose what s/he does. However, it is a matter of priority. In the long run, of course, the child or young person has to be taught to 'obey' the teacher and follow the curriculum, even when s/he does not want to, but that is a long-term teaching goal. In the meantime the child has developed a very difficult and somewhat dangerous behaviour (repeated head banging can lead to detached retinas and blindness), and surely the priority is to give him/her a more acceptable way of indicating that s/he does not want to do the task? Even children with good language skills may not be able to do this using speech when they are very upset. Thus, we teach the child an 'easy' alternative; we support him/her in doing this (perhaps with a visual prompt) and we demonstrate that this response is just as effective as head banging in getting rid of unwanted demands (necessary if it is ever to replace the head banging). Once this is accepted and has become routine for the child, s/he is liable to be calm and we can then begin the process of indicating we understand s/he does not want to do this now but, if s/he just does this bit (clearly

visible) or for this long (marked with a timer of some sort) then s/he can do something s/he likes (indicated by a visual schedule).

2.9.4 Understanding the history of a behaviour

It is also worth trying to work out the history of the behaviour. This will help with determining its function (or many functions), and will give an idea of whether it is a new behaviour, has occurred in the past and is now back again, or is a long-standing problem. This will help in understanding its functions, but will also enable staff or parents to find out what has been tried in the past and how the child or young person responded to different strategies. This will not only show instances where challenging behaviour has been reinforced so it is now well established (even more of a problem if the individual is sometimes reinforced for a behaviour and sometimes not), but will also help to show what meaning the behaviour has for the child or young person.

2.9.5 Transactional Processes

The term 'challenging behaviour' is meant to signal a move away from notions such as 'problem' or 'difficult' behaviour, which is taken as an attribute of the child or young person, rather than as an interaction. Thus practitioners also need to examine their own reactions and how these may be contributing to the situation. This is not just about behavioural responses but also emotional reactions. People with AS may not be good at identifying emotions in themselves or others, but they can be very tuned in to how people are really feeling, rather than the 'social face' they have constructed. Thus they may pick up on bodily signs of fear or displeasure, even when the adult is trying to indicate through a passive expression that s/he is not (for example) bothered by the child spitting at him/her.

It is understandable that a child or young person with AS who may have so many advanced skills can evoke feelings of frustration and even hostility in staff who find it difficult to appreciate that their social and emotional understanding may be less than that of a young toddler. It is worth acting 'as if' the child does not understand (even when staff are convinced s/he can) because this is usually the best way of demonstrating how much better things are (for the child, the class and the teaching staff) when we do spell everything out and make it visually clear to the child what to

do, where, with whom, for how long and what next (as in the TEACCH approach). A teacher in a mainstream class (as demonstrated in the DVD on autism produced jointly by the Departments of Education in Northern Ireland and the Republic of Ireland) can make a great difference to compliance just by reinforcing verbal instructions with written ones on a post-it, or can stop a child shouting out and correcting the teacher (common problems in AS) simply by giving the child a clear strategy (writing down 'corrections' in a notebook to be discussed with the teacher later) to deal with the problem. People with AS find it hard to simply inhibit actions, so behavioural control means telling them what they *are* to do rather than what they are *not* to do (e.g. *sit on the chair, rather than get off the table; walk rather than don't run*).

2.9.6 Positive approaches

This positive approach to managing behaviour is both more humane and more effective. Individuals with AS like rules, and they are often anxious to follow rules exactly (and to make sure others do), even when a more relaxed attitude might be more appropriate. At the same time, they find it difficult to obey *people*, because that means they have to give up control to someone whose behaviour and intentions they do not understand. Thus, the child with an AS may happily obey a written rule (and the more formal this is the better), but will argue and resist if told to do something by someone else. It is better for everyone, and far less stressful for the child if, instead of trying to force compliance to spoken instructions, these are presented in a visual form, and especially as an 'objective 'rule' that all must obey.

Even at the age of ten or older, some children and young people with AS may not have been taught to respond to their name as a social signal to gain attention or, even if they have, the teachers and carers forget to use it as a signal (or do not understand the importance of doing so). Thus a teacher may become upset when the child fails to respond to a command phrased as '*Put your books away, Conor!*', not realising that the attention-gaining signal (i.e. his name) is at the end of the phrase and the child will not have been paying attention until that word was heard.

Practitioners have to train themselves to use the attention signal first, give time for an attentional response, and then give the command.

2.9.7 Stress and Exhaustion

It should also be remembered that social interactions require cognitive effort in children and young people with AS, so they are likely to be exhausted simply by having to engage with others after a day in school. Add to this the difficulties in puzzling out what people mean, what s/he is expected to do, worrying about when it might be over, and all of this on top of any academic work; it is not surprising that levels of stress rise throughout the day in school. Wherever possible it helps to have some aerobic activity (20 minutes) to help dissipate this stress and allow the child or young person to focus once more. They can also be taught simple relaxation techniques such as folding arms with hands tucked in; this calms the child physiologically and also prevents automatic hitting out at self or others when anxious, thus making it easier to put in place rehearsed strategies for managing stress.

Often the child or young person with AS will need to have some time out from a busy classroom for a while. It is best if the teacher manages this (Jordan, 2003) so the child or young person learns to go out to an approved and time-limited calming activity, rather than simply running off or using an emotional outburst as a way of gaining release.

It should be remembered that when an individual with AS 'erupts', it may be the result of a particular trigger, but is more likely the fact that it is the last straw in a series of stressful events. The child is at the end of his/her tether in terms of stress, and the eruption is as much a result of what has gone on some time before as it is a reaction to any immediate factor in the situation. On the other hand there may be particular sensory stimuli (e.g. children shouting, chairs being scraped back, particular smells) that are triggers for uncontrollable stress, and it is kind to try to identify these and see what can be done to help protect the individual from these.

Clements and Zarkowska (2001) offer further insights into causes of challenging behaviours in ASD and strategies for managing them. Jordan (2003) also illustrates how it is possible to help individuals with AS, especially as they grow towards more independence, to begin to take some responsibility for their own actions. Without this kind of support, children with AS often feel aggrieved by any sanctions imposed on them and do not understand at what point they could have changed the outcome.

They need to be brought (through a flow chart) to understand that it is no use railing against the final outcome; that is too late. They need to plan their actions so they end with the outcome they want. In this way, challenging behaviour is reduced but it also helps them understand more and become aware of how they can manage their own behaviour. Social Stories (Gray, 1998) and other similar strategies also help them to understand and manage situations which might otherwise have become beyond their control.

2.10 Prevalence and numbers of children and young people with a diagnosis of Asperger syndrome living in Northern Ireland

It is not possible given current diagnostic practice, and the instruments and methods of recording Asperger syndrome, to establish the exact numbers of children and young people with Asperger syndrome living in any geographical area, should this be in Northern Ireland, other parts of the UK or the world.

- There is no definitive method for confirming diagnosis and the rates of diagnosis vary across areas in all countries of the UK and elsewhere;
- The needs arising from AS may require support from health, education, social services, the voluntary sector or all four, and so different lists of children and young people with AS will exist within agencies;
- Databases are not shared between agencies; and
- Often, even within an agency, there is no one person who has access to all the data on a particular group of children and young people, in this case AS, and so gathering data is difficult.

Currently, those working in different agencies and services in the UK and elsewhere often keep their own database on children and young people with AS, so that within the same geographical area, there may be several registers or databases on which the same child or young person might appear, held by education, health, social services or a voluntary organization. Time and money is potentially wasted in having

several databases. Having one central database that all can share would aid planning and resource allocation. However, there are some serious ethical and logistical issues to resolve here, so as yet, it remains a desirable but distant goal. In the north-east of England, an attempt is being made to create a single database (known as DasLne (Database of children with ASD Living in the North East) across all agencies to record children with a diagnosis on the autistic spectrum (see website for more details www.ncl.ac.uk/daslne/).

2.11 Regional differences which may exist

Whenever studies are conducted on the numbers of children with AS or an ASD living in a particular area, there are always considerable differences in the rates of identification across authorities and health trusts (NIASA, 2003). This is largely due to differences in expertise amongst professionals and in awareness of AS and ASD generally.

There are different challenges in supporting families in rural and urban areas and often there can be more services around large cities and the capital of a country, as the higher populations create more parents and professionals who demand that something more or different is provided. Rural and urban areas will have different challenges, in that families with a child with AS will be spread over a wider geographical area in rural regions, making services less efficient in terms of travelling time and viability of services. However, in some respects there may be fewer demands on families with a child with AS in a rural area than in a relatively overcrowded, busy city area with little open space for leisure activities. It may also be that informal family networks are stronger in the rural communities where there may be less mobility between families.

2.11.1 Variation across areas in service provision

Currently, services offered to families with children with AS in the UK and elsewhere in the world vary depending on the area in which they live (Howlin & Moore, 1997; DES, 2002; NIASA, 2003). However, in the last decade, much energy has been put in to providing resources, services and training in ASD in many areas to enhance these. Practice and identification has therefore improved in Northern Ireland, the

Republic of Ireland, England, Wales and Scotland. Two clear signs that services are improving are that the age at diagnosis is decreasing and the numbers of children being identified with ASD is increasing (Howlin & Moore, 1997).

2.12 Consequences of improved identification of ASD

One of the issues in improving practice for the identification of AS and ASD is that more children and young people are identified and found to be in need of a service. So there is a need to increase the number of professionals who have knowledge and experience of ASD and who are asked to take responsibility for meeting their needs.

2.13 Diagnosis, assessment procedures and interventions in Asperger syndrome

There have been many recent working parties and reports conducted within different areas and authorities in the UK and nationally on diagnostic assessment of ASD (e.g. NIASA, 2003; SIGN, 2006). As a result, there is a broad consensus on how a diagnostic assessment should be carried out and what should follow. Services and practice for those with Asperger syndrome are included within these, and only given a separate mention where this is felt to be necessary.

The National Autism Plan for Children (NIASA, 2003), produced over a two year period by a working party in England, is a very useful document for providers, parents and policy makers. This recommends multidisciplinary assessment by a local team of professionals with specific training in ASD. Assessment should include a detailed history, including the family history, observations of the child/ young person across different settings and situations, and the collation of reports from all those who know the individual. When a parent expresses a concern about their child, professionals need to discuss in detail the nature of this, assess what reasons the parent thinks might underlie this delay or difficulty, and offer advice on what to do next, other than 'wait and see.' It is often useful to ask the parent to observe particular behaviours in more detail and then report back. Where the professional is not sure, then referral on to more experienced professionals within Education, Health or Social Services is necessary. More recently in Scotland, a similar working party has been meeting to draw up SIGN (Scottish Intercollegiate Guidelines Network, the

equivalent of NICE (National Institute of Clinical Excellence) in England) which provides guidance on assessment, diagnosis and interventions in ASD. This was launched in October 2006.

These working parties were set up because it was recognized that diagnostic services in ASD had developed in a rather ad hoc manner throughout the UK, depending on local expertise and priorities, so that some families received a very good service and others were not well served at all. In addition, knowledge and understanding about ASD has changed and increased, and there was a need to develop national guidance so that policy makers and planners could use this as a framework in future planning and resourcing.

Resources were given to the four Health Boards in Northern Ireland to conduct a similar exercise on diagnostic assessment, but the Special Interest Group on diagnosis and assessment felt that insufficient money was given to undertake this and so, as yet, an agreed strategy or protocol has not been produced.

2.13.1 Delays in diagnosis

There are still many children with AS in the UK in mainstream schools without a diagnosis who would benefit from one. However, identification is rising as awareness increases. For some children, the diagnosis can be made fairly quickly, but for other children with more complex histories and behaviours, the process takes longer (NIASA, 2003). Parents may opt for private assessment by independent psychologists if they feel that they will have to wait too long or they disagree with the diagnostic opinion of local professionals. This is an expensive option and does not always work in the family's best interests as the independent professional may lack knowledge of provision local to the child, and any recommendations made might not be taken up by statutory services. In the current climate, there is always likely to be a market for independent and private work, but as statutory services improve, the need for this will decline.

In some cases, the delay in diagnosis is not because there is a waiting list but because the professionals do not recognize the child has AS, or because they are not sure enough to give the diagnosis. There are two points to make here. The first is

that it is essential for all those who work with children and young people to have some training in what the NIASA report (2003) refers to as the 'alerting signals' in ASD and then to know whom they might refer on to. The second point is that for some children/young people, it is difficult to detect AS and even an experienced professional may not be sure.

As discussed earlier, diagnosis of AS is done on the basis of observation of the child's past and current behaviours, and on the reports from parents and professionals. There is no definitive medical or psychological test which can confirm the diagnosis. Screening instruments, diagnostic tools and checklists have been developed, but none of these can reliably confirm that a child has or has not AS. For children with AS, it can be particularly difficult as they may be very skilled in certain areas and their ability can mask their problems. If assessment and information is limited to a single appointment with a GP, a psychologist, or a psychiatrist, their difficulties may not be picked up. The key areas to question are their social understanding and inclusion with peers, their ability to communicate with familiar and unfamiliar people on a range of topics, their flexibility in thinking and behaviour, and their level of anxiety and signs of depression. Children and young people with AS are more likely to experience anxiety and depression than other children (Gillott et al., 2001; Kim et al., 2000), so this might be an alerting signal too.

As diagnostic assessment improves, there is increased pressure on services to provide for more children and young people at an earlier age. In the future more resources will be required to support children and young people with AS and their families. Some parents of children with ASD and other conditions have given this as a reason as to why professionals deliberately maintain waiting lists (i.e. so that they do not have to spend money on resources to address the needs identified), but the more likely reasons for delayed diagnosis is that professionals do not recognize the signs of AS and/or that there are insufficient people in post.

2.14 Screening instruments for ASD

Screening instruments which have been developed to try to detect ASDs in the early years include the CHAT (Checklist for Autism in Toddlers), the M-CHAT (Modified CHAT) and the CAST (Childhood Asperger Syndrome Test) (Scott et al., 2002).

As yet, none of these are considered to be sufficiently reliable to advocate the screening of whole populations (Health for all children, 2003), and would miss some children and lead to false positives (i.e. with resources being allocated to those who may not benefit from these). Some authorities in England have used these screening tools as a basis for training primary health carers such as health visitors and GPs in the signs of ASD.

2.15 Access to services and differences between families

Families' ability to access services varies. There is a realization that some families find it easier to access services and support than others due to factors such as location, transport, literacy levels, ethnicity, and social class. It is likely that 'advantaged' families are more likely to receive a diagnosis of AS than others and at an earlier age. All services need to review how well they deliver to all families throughout their area. Similarly, good practice can be trapped in particular centres, schools and services, and it is important to consider how this can be effectively shared.

2.16 Information given to parents at diagnosis

Research has shown that some parents are given little or no information at diagnosis and others are provided with an excellent information pack about ASD and local support (West Midlands Regional Partnership, 2002; NIASA, 2003). Parents usually have many questions to ask, but may be in shock or may not be given the time to ask these. Some parents say they would like another appointment soon after diagnosis to discuss issues further. In addition, it may only be the child's mother who receives information first-hand and the father of the child can be (and/or feel) excluded from the process. Where possible, at diagnosis and in training events for parents, consideration should be given as to how other family members might be included and enabled to access these. This is already happening in some areas where

grandparents are invited and where training events are offered to both parents (with child-minding provided), and seminars are held separately for fathers and siblings. In addition, advice to parents on how to help after the diagnosis is given is often not given soon enough. The recommended time scale in the NIASA report (NIASA, 2003) is 6 weeks from diagnosis. This does not mean that an intervention for the child or young person or the parents has to start then, but that discussion with the parent on how to help, preferably with supporting literature, will have occurred. For a child or young person where the diagnosis is unclear, intervention does not need to wait for diagnosis, as some areas of need will be evident and can therefore be acted upon before the diagnosis is confirmed.

2.17 Demands on parents and families

A child or young person with AS might appear to ignore or avoid parents in the early years and beyond. Parents can be hurt by the social isolation/rejection of their child by other children and other parents. An issue in the inclusion of children and young people with AS in mainstream schools and colleges is sometimes persuading other parents that their children will not be adversely affected. Some behaviours of children and young people with AS are very distressing to parents and siblings, and extremely stressful to live with (e.g. repetitive behaviours; fixed routines; incessant questioning or arguing the point; self-injury; refusal to follow family routines or wishes leading to huge family arguments). Not knowing exactly what/when the child or young person might find it all too much has been described by one parent as '*walking on eggshells permanently*'.

For many children and young people, there is a need for much greater supervision and attention by parents and others than for other children of a similar age. Parents may not be able to leave their child unattended or go out together as a couple or as a family unit. It may not be possible for the parents to have time alone without their child, they may have no friends outside of school to be with or it may not be safe. Some parents say they continue to worry even when their child is at school, in case there is a problem. Concerns about safety and difficult experiences in the past can reduce the extent to which families visit their friends and relatives and access facilities generally.

Rather than training or resources on specific interventions, many parents would welcome ‘another pair of hands’. Some children and young people are offered a befriender, but such schemes are very limited and in their infancy, and tend to be offered by charitable or independent organizations rather than the statutory services.

2.18 Multi-agency collaboration

There are potentially many different professionals and agencies who need to be involved with a child or young person with AS: those who assess and meet the needs arising from AS, and those not related to AS (e.g. dentists, GP, opticians, school nurse). It is essential that ways to collate and disseminate information are found to ensure that the child or young person with AS receives appropriate support and to avoid repetition and confusion in what is provided and recommended to parents and others. Asperger syndrome is often referred to as an ‘invisible disability’, so that others literally cannot see that the child or young person has a problem. Other explanations may then be given for the child’s behaviour. Parents and/or the child or young person may be blamed and criticised for their behaviour and attitude by the school, college or by other family members PRIOR to diagnosis. Some professionals and teachers in schools and colleges may still hold this view, even after diagnosis, as the child or young person appears to be so ‘normal’ in other ways that their inappropriate and unacceptable behaviour is seen as a deliberate breaking of the rules.

Figure 1 shows the type of professionals who might be directly involved with the child or young person and the family to meet the needs arising from AS. Figure 2 shows the professionals whom the child or young person might meet for other reasons.

Figure 1: Professionals and agencies whom the child/young person might meet to address the needs arising from Asperger syndrome

Professional
Befriender
Careers officer
Classroom support assistant

Clinical Psychologist
Dietician
Early years teacher
Escort
GP
Headteacher
Occupational therapist
Paediatrician
Physiotherapist
Psychiatrist
SENCo
Social worker
Speech and language therapist
School transport driver
Voluntary worker

Phillippa Russell, past head of the Council for Disabled Children whose son with learning disabilities who is now in his fifties, has said that by the age of 5 years, some children and families with a child with a disability might have met up to 20 different professionals. The scope for conflicting advice and confusion is obvious, and multi-agency coordination and some form of key-working system for families where many professionals are involved is vital. In addition, she has estimated that her son has been assessed (for a variety of reasons, including financial allowances) over 400 times in his lifetime. She makes the point that this has been very expensive and questions whether every assessment is wholly necessary. Less money spent on assessment would release money for services for children and families. Clearly, it is important to make an assessment to establish the nature of the needs, but this statistic does give pause for thought and prompts professionals to work in a way which avoids repetition and to ensure that work undertaken has a clear rationale.

Families often feel abandoned by services after diagnosis or a time-limited intervention such as parent training or group therapy sessions, and have to work hard or publicise their personal stress in order to get an agency re-involved. In a

Child and Adolescent Mental Health Service in the West Midlands, there is a recognition that some families will continue to need support over the years, and so staff leave the child’s file open. After an intervention, parents are told they can phone the office at any time in the future if they feel the need for support again. This is very reassuring for parents and has not led to a large increase in re-referrals.

Figure 2: Professionals whom the child/young person with AS might meet to address needs Unrelated to Asperger syndrome

Professional
Community personnel
Dentist
Employer
GP
GP receptionist
Hairdresser
Health visitor
Hospital staff
Leisure Centre staff
Optician
Practice nurse
School nurse

The NAS has produced a very useful booklet for health professionals (Deudney, 2006). NES Scotland, too, the educational and training branch of the NHS in Scotland, has produced a website resource and leaflets on ASD for primary health care practitioners (see www.nes.scot.nhs.uk/asd) which was launched in 2006. The leaflets cover how to understand and support a person with an ASD during an appointment, the action they might take if they suspect a person has ASD, ideas on how to support the family and information on associated conditions.

Other professional groups who need to be informed about AS include the police so that if a child or young person comes to their attention, they are managed effectively.

Some local and national autistic societies have created cards which individuals with ASD can carry with them to give to the police or to others if the need arises. These usually have the logo for the local police force to show that the police are aware of this group. An example of such a card is that produced by Autism Cymru. This card carries the website and telephone of the organization, the police force logo and simply states:

- I have an Autism Spectrum Disorder;
- ASD is a disability;
- I may need access to an intermediary;
- Please ask questions one at a time; and
- Please tell me step-by-step what is to happen.

The London Metropolitan Police Force is to give sessions on ASD to all 30,000 officers in the force over the next few months, initiated by an Inspector who is the father of a child with ASD (Perry, 2006).

2.19 Policy, guidance and reports on ASD in Northern Ireland

2.19.1 Educational policies in Northern Ireland on Asperger syndrome

From an educational perspective in Northern Ireland, Asperger syndrome comes under the remit of special educational needs (SEN). Guidance for recording children with SEN (Department of Education, 2005) places Asperger and Autism in Category 3, 'Communication and interaction needs', but this is essentially administrative in nature and intent. SEN legislation largely mirrors that in England and Wales. There is a historical bias towards the medical, within-child, model of disability, with a more recent shift towards increasing inclusion based on the social model which suggests that attitudes and the environment are a major factor in disability. This change and that within society at large have developed together because of the equality and antidiscrimination policy and legislation that has been introduced in recent years (Hunter & O'Connor, 2006).

There are two main differences between the provision in Northern Ireland and that in England and Wales which influence inclusive practices (Kilpatrick, 2006). These relate to the religious segregation of schooling and academic selection. Education and Library Boards (ELBs) are responsible for controlled schools which are attended mainly by protestant children. These are roughly equivalent to local authorities in England and Wales. Catholic children usually attend maintained schools, owned and maintained by the Council for Maintained Schools (CCMS). As a result of the political conflict in Northern Ireland, there has been a move towards religiously-integrated schools. This has led to just under 50 grant-maintained, integrated schools being set up (Kilpatrick, 2006). Academic selection occurs at the age of 11 when the pupils take a test to determine whether they will be one of the 33% attending a grammar school or if they will go to a secondary school. This system is due to be phased out in 2008/9 (Kilpatrick, 2006).

The main legislation that impacts on SEN includes the Education (Northern Ireland) Order 1996 and this has been amended by the Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDI). Under these, the statutory responsibility for securing provision for pupils with SEN rests with the Education and Library Boards and the Board of Governors of mainstream schools. The Review of Public Administration might change this (see www.allchildrenni.gov.uk).

From 1998/99, a Code of Practice offering guidance on the identification, assessment and monitoring of pupils with SEN, similar to that in England and Wales, was introduced so that most children could be identified and have their needs met within mainstream schools. This was in support of the Education (Northern Ireland) Order 1996. Schools, Boards and Health and Social Services authorities must consider the advice given in the Code of Practice when deciding what they should do for children with special educational needs. The Code of Practice offered a 5-staged approach, matched to individual need, with the final stage being a Statement, issued by the Education and Library Board setting out the additional provision required to meet these needs. The Code of Practice encouraged education in mainstream schools, whilst recognising a continuum of need which could be matched with a continuum of provision. The views of the child were to be taken into account in line with Articles 12

and 13 of the United Nations Convention on the Rights of the Child, and schools were to work in partnership with parents.

A supplement to the Code of Practice has been issued, effective from 1st Sept 2005. This offers guidance on working with the changes brought about by SENDO. These changes include strengthening the rights of the child to an education in mainstream education, the provision to parents of more advice and information, and a means of resolving disputes (Hunter & O'Connor, 2006). The efficient education of all students however, is protected. A continuum of provision is still envisaged with the roles of special schools being recognised and valued. Inclusion is deemed to be more than a placement, and a parent's right to send their child to special school should not be reduced by the strengthening of their right to a mainstream place.

Part 3 of SENDO also applies the Disability Discrimination Act 1995 (DDA) to schools and colleges. This gives pupils the right not to be treated less favourably or to be disadvantaged because of their disability. Schools and colleges must also increase accessibility to the premises, the curriculum and written information provided for students. Their admission arrangements should not discriminate against disabled children and young people.

Future changes that should impact on the provision for those with SEN include a revised framework for the curriculum which comes into effect, alongside the end to selection, from 2007 and is strongly pupil-centred. Those with SEN should have access to the same learning pathways as other pupils (Hunter & O'Connor, 2006). The recent requirement for schools to have a School Development Plan (SDP) may also impact on SEN provision. Although intended to standardise school policy and planning, and linked to self-evaluation, SDPs will provide an opportunity to reconsider current ethos and practice (Hunter & O'Connor, 2006).

As yet, there is no equivalent in Northern Ireland to Every Child Matters (DfES, 2004) in England and Wales. Consequently, there is no policy directive aimed at integrating the children's services currently provided by the Departments of Health, Social Services and Education (Kilpatrick, 2006). The strategy document published in 2006

for children and young people entitled, '*Our Children and Young People: Our Pledge*,' may help to address this (see www.allchildrenni.gov.uk).

2.19.2 Report on ASDs from the Health and Social Services Boards (HSSB)

There are currently four health and social services boards within Northern Ireland, Northern, Southern, Eastern and Western, which are further broken down into Trusts. This might change with the Review of Public Administration. In July 2003, the four boards wrote a position paper on ASD entitled, '*Four Board Paper on the development of autistic spectrum disorder services: diagnosis and early intervention*'. This identified the major issues in providing effective and timely services for children and families and recommended future proposals, sometimes in the form of a pilot project.

The main difficulties in providing the good services identified were long waiting lists, shortage of personnel, lack of training in ASD, and a failure to work in a multi-agency way for some of the reasons mentioned. The importance of linking diagnosis to intervention was stressed and links with the voluntary sector were seen as essential in providing support for parents and training.

The report on the Keyhole project (McConkey et al., 2003) by the University of Ulster and PAPA (Autism NI) reported on the benefits of giving families ideas on how to develop communication, and how to understand and manage behaviour. Giving a diagnosis in isolation, with little or no follow-up or advice on how to help the child, is not good practice.

This present Review found that much recent work has been done in Northern Ireland to improve this situation in a number of ways and so parents in the future should be better informed and supported.

The five ELBs ASD Advisory Teams have each produced their own packs for parents containing leaflets on local services, useful strategies, checklists to complete on the child to identify strengths and needs (e.g. from Cumine et al., 2000), websites, and articles on AS (e.g. Attwood, 2002 on friendships) and on how to look after

themselves, as parents. In addition, Autism NI, has created Rainbow Resource Kits for use by parents of young children with ASD in the early years.

2.19.3 The Bamford Review on Mental Health and Learning Disability: ASD (2006)

The recent Bamford Review produced in May 2006, has set out a 10-year plan, looking at mental health services and learning disability services in relation to children and adults with ASD. The point is made that currently the needs of those with ASD are being met by a number of different services – Learning Disability Services, Mental Health Services and other programmes, while ‘*some needs are not being met at all*’ (p.2). It makes a number of recommendations, often giving similar advice to that contained within the National Autism Plan for Children (NIASA, 2003):

General recommendations in relation to diagnosis and assessment

- Autism specific diagnostic and assessment services must be established in each Trust;
- Providers should offer ASD specific diagnostic and assessment services for children and adults, regardless of intellectual ability;
- Professionals must be highly trained in child development and relevant disorders, including mental health problems;
- Expertise in relation to adults with Asperger syndrome and HFA needs to be developed;
- Child and Adolescent Mental Health professionals must acquire greater knowledge and experience in assessment and diagnosis of ASD; and
- There should be a clear pathway to diagnostic and assessment services for families once ASD is suspected.

The Review makes the point that the needs of people with ASD can span several programmes of care, and poor coordination of these can affect effective service delivery.

However, the Review does not then recommend that a separate programme be developed specifically to take responsibility for ASD, as they feel this would divert scarce resources and marginalise individuals with ASD. Instead, the Review recommends that:

- The Learning Disability programme should be responsible for service development for those with ASD and learning disabilities;
- The Children's Services programme should be responsible for children and young people with ASD; and
- The Mental Health Services programme should take responsibility for adults with ASD.

Some professionals, however, and those within Autism NI are very concerned with this latter recommendation in particular and are currently challenging it. The main bases for the challenge are that ASD is not a mental health disorder per se, and that those working in mental health services are often not very knowledgeable about ASD. Families and children and young people with AS, and adults with ASD, may therefore be misunderstood and interventions offered may be inappropriate. What Autism NI and some other professionals in Northern Ireland would prefer is what the Review did not support – that is, a separate team to work with individuals with ASD, and an Northern Ireland strategy for ASD, together with a 'ring-fenced' budget and legislation to protect their rights. Autism NI has successfully campaigned to have autism removed from the mental health programme of care. At a lobbying event in Whitehall on 29th March, 2006, the Secretary of State for Wales and Northern Ireland, Peter Hain overturned the ruling that autism be part of mental health. Since then, Autism NI has been actively campaigning for a separate programme of care for ASD.

2.19.4 Educational Reports on ASD

2.19.4.1 Education and Training Inspectorate (2001): A Survey of Pupils with AS in Primary and Secondary Schools in Northern Ireland, 1999-2000

This survey was designed to look at the numbers of pupils with AS in mainstream primary and secondary schools, to evaluate the effectiveness of approaches to meet their needs and to identify areas which needed to be enhanced. Data were collected from classroom observations, and from interviews with staff, including SENCos, and educational psychologists. Discussions with groups of children which included a pupil with AS were held. Twenty-four schools were visited.

At the time, there were 342,895 pupils in mainstream primary and secondary schools in Northern Ireland, 160 of whom had a diagnosis of AS. This would give a figure of 5 per 10,000 which is much lower than the rate of 36 per 10,000 recorded by the ELBs today. The rate for the NEELB was much lower than for the other ELBs. The report in 2001 stated that these pupils were identified through the statutory assessment process. It is not clear from this whether these are only the pupils with Statements, or whether it includes pupils with AS who were at earlier stages of assessment on the Code of Practice.

The figures for each Board are shown in Table 1.

Table 1: Number of pupils with AS in mainstream primary and secondary schools in 1999 in each of the five Education and Library Boards

1999 Data			
Board	Pupil population	Number with Asperger syndrome	Rate per 10,000
Belfast	56,865*	39	7
Western	58,747*	33	6
Southern	72,165*	28	4
North Eastern	65,000	4	0.6
South Eastern	66,785	56	9
TOTALS	319,562	160	5

*2006 figures used, as the 1999 figures were not available

The numbers of children identified as having AS varied considerably across the five ELBs in 1999 suggesting that diagnostic practice also varied.

This variation may be the result of a difference in:

- Criteria used for making a diagnosis of Asperger syndrome;
- Expertise in recognizing suspected AS by primary health care workers such as GPs and health visitors; and
- Expertise in making a diagnosis of AS by paediatricians, psychologists and psychiatrists.

The ETI concluded that,

'It is the view of the Inspection Team that present numbers (of pupils with AS) appear to be significantly underestimated in the Province as a whole' (p.3).

At the time of the survey, the Department of Education did not hold a database on the numbers of children by category or disability. Since then, it has created a database so that data on all children diagnosed with 'a disability or difficulty' (DE, 2005) is reported by schools and held by the Department. This will be extremely useful for exploring regional differences.

2.19.4.2 A comparison with data taken from Education Authorities in the West Midlands in 1999

The 14 education authorities within the West Midlands region of England were asked to provide data on the numbers of pupils they had with a diagnosis of ASD. They were asked for separate figures for autism and learning difficulties and for those with AS or HFA. Four authorities did not provide any data on these, seven had the data combined for both diagnostic groups and so did not have separate figures. The remaining three were able to give data separately on AS/HFA and these figures are shown in Table 2, to act as a comparison with data from the five Boards in Northern Ireland and to show that in England, many authorities do not yet have easily accessible and accurate figures on the numbers of children with AS.

Table 2: Numbers of pupils with AS/HFA identified in three Education Authorities in the West Midlands in 1999

Education Authority	Pupil Population DfEE Jan 1999 4 to 18 years	Total AS/HFA Identified 1999*	Total AS/HFA expected if 36/10.000	Rate per 10, 000	Total ASD in 2006+	Rate per 10,000 using 1999 population figures
Sandwell	52,827	44	190	8	61	12
Staffordshire	138,548	92	498	7	273	20
Walsall	51,112	30	184	6	84	16

Source: *West Midlands Regional Partnership; +DfES
HFA High Functioning Autism
DfEE Dept for Education and Employment

The rates of identification in these West Midlands authorities are very similar to those recorded in Northern Ireland in 1999. The totals for AS/HFA are lower than expected given the prevalence rate now suggested from epidemiological studies, and illustrate the problems in identification and diagnosis of the able group of children and young people with AS/HFA. As mentioned earlier, Howlin and Moore (1997) found that the average age at diagnosis for children with AS was 11 years, so if that were true for these three authorities, many children in the primary years would not be identified. There is another proviso here in that these data come from education only, and if health and social services had contributed their data, these rates would rise. Having separate databases makes it difficult to arrive at accurate and reliable figures.

2.19.4.3 Other findings from the study of Asperger syndrome by the ETI in 2001

Positive findings

- There was a growth in the development of multi-agency assessment teams; and
- Skills and knowledge of educational psychologists were developing.

Neutral findings

- All five boards reported an increase in the number of pupils with ASD, particularly at the pre-school age, partly due to an increased awareness of the condition.

Negative findings

- There was confusion amongst professionals as to who should make the diagnosis;
- Making the diagnosis often took a great deal of time; and
- There seemed to be little concerted effort amongst the Boards (Education, Health and Social Services) to address the issue of identification at policy level and to establish procedures and protocols for resource allocation.

Social development of pupils with Asperger syndrome

Many teachers were unsure of what to do to help develop the social and emotional understanding and skills of pupils with AS, particularly for the older children. Many older pupils felt isolated at break times and in physical education.

Conclusions

'The issues relating to definition, diagnosis and consistency represent a significant challenge that the Department and the area boards have to address jointly' (p.6).

Provision

The quality of provision varied considerably from largely satisfactory to good. There was some excellent practice and some areas where the child's needs were not being met. It was noted that the Boards Curriculum and Advisory Service (CASS) was developing and providing good support.

Alongside the good practice, the weaknesses in provision were summarized thus:

- Schools do not plan ahead and tend to deal with problems as they arise;
- Schools and Boards give little consideration to the long-term implications of the condition;

- Few teachers have a clear or in-depth knowledge, or range of appropriate skills, to plan for the specific needs of pupils with AS;
- Many teachers consider the problem is largely one of accessing the statutory curriculum, and of settling behavioural difficulties;
- Few schools involve parents effectively in the programme;
- The advisory officers cannot respond adequately to the demands made of their service; and
- Teachers are generally working without the continuous guidance and support which they need to cope with pupils with AS.

A significant finding of the survey was that pupils with AS were more at ease in a school setting where their needs were considered at a whole-school level, and where all staff had an agreed set of strategies to support the pupil, in combination with the provision of a highly-structured, predictable environment and routines.

The ETI (2001) stated that there was,

'A need for written guidance, including planning and evaluation strategies, and practice exemplars'.

These have now been produced by the Department of Education and published in two documents entitled *Autistic spectrum disorders: a guide to classroom practice (DE, 2003)*, and *Evaluating provision for autistic spectrum disorders in schools (DE, 2005)*. In addition, the DfES in England (DfES, 2002) published guidance in 2002 on how the needs of pupils with ASD might be addressed at the three levels - the region, the local authority and the school or unit.

2.19.4.4 Department for Education and Science (2002). Educational Provision and Support for Persons with Autistic Spectrum Disorders: The Report of the Task Group on Autism

In Northern Ireland in November 2000, a Task Group was set up by the Department of Education. This was established to make recommendations on the educational provision for children and young people with autism and Asperger syndrome in Northern Ireland. It reported in 2002, noting that the issues were multidisciplinary and therefore applied to Health and Social Services as well as to Education. It made recommendations in three main areas, cross-disciplinary cooperation, training for parents and providers and the provision of in-home and in-school educational and therapeutic provision.

Some of the key recommendations of the Task Group which relate particularly to those with Asperger syndrome are as follows:

- Educationalists should recognise that education has a central role in *'remediating the effects of ASD and improving the quality of life for individuals throughout the lifespan'* (2 (i) p.25).
- The central factor in educating an individual with ASD is to understand the nature of the disorder (2 (ii) p.25).
- Early diagnosis should be available and should include an accurate and comprehensive assessment from which appropriate educational and health interventions are developed (2 (iii) p.25).
- Teachers and others contributing to programmes should be provided with relevant information arising from the diagnostic assessment process (2 (iv) p.26).
- Social skills training should be provided as an essential element of intervention programmes for children and young people with ASD (2 (vi) p. 26).
- The learning strengths and weaknesses of children and young people should be identified to ensure effective differentiation of provision; an emphasis on visual

communication, simple and clear use of language and constant routine are of particular value when teaching children with ASD (2 (vii) p. 26).

- Interventions should focus on the development of strategies which structure the environment to provide the child with a sense of security conducive to learning appropriate behaviours in a range of settings (2 (viii) p. 26).
- Teachers and others should understand the sensory difficulties which children may experience as a consequence of ASD, and set appropriate targets to address each child's sensory needs (2 (ix) p. 26).
- Intervention programmes should address the issue of anxiety and stress as a normal consequence of ASD (2 (x) p. 26).
- There is a need to work more closely with parents and parent bodies to secure their active participation in the planning, management, delivery and evaluation of services, and to reassure them that statutory provision will meet their children's needs (p. 28).

In relation to the planning of provision by the ELBs, it is recommended (on pages 53-54 of the Task Group report) that provision should be:

- Based on current research indicating best practice in respect of achieving meaningful outcomes, providing value for input of time and resources, and promoting independence and inclusion;
- Inclusive of a range of methods and approaches which have been shown to be effective or which are judged by those who work with children with ASD to be worthy of evaluation;
- Determined by, and regularly reviewed by, multi-disciplinary, multi-agency teams which include parents as well as appropriately trained professionals from

the ELBs and HSSBs, and which respond promptly to requests for assessment and intervention;

- Reflective of the individual's needs profile, and any changes in these needs over time and across different contexts, and should be reflective of the needs of the family;
- Compatible with the Department of Education's pastoral care, including child protection guidelines (Circular 1999/10) and the United Nations Convention on Human Rights (Article 4);
- Provided by appropriately trained professionals, and by parents who have also had appropriate training;
- Subject to review, evaluation and inspection by the Education and Training Inspectorate.

2.19.4.5 The Education and Training Inspectorate in the Republic of Ireland (2006)

This year, the ETI in the Republic of Ireland, completed a two year evaluation of four different educational settings for children with ASD and identified the strengths of each type of provision, in addition to pointers for each to consider (DES, 2006). This focused mainly on the early years and primary age group and did not comment separately on children with AS or HFA.

The study looked at four ABA centres (with 77 children aged from 3 to 9 years); two schools specific to ASD (with 45 children aged from 4 to 13 years); ten special classes in mainstream schools and eight primary schools which each included a child with an ASD in ordinary classes (aged between 7 to 10 years). Three of these children had AS.

Some recommendations were made in relation to all four settings. In summary, there was a need to ascertain the children's sensory responses and needs; to train staff in specific approaches; to work in a more multi-disciplinary way; to involve the parents in the IEP; and to extend the use of ICT. There are now many interventions and

several books on AS and it was acknowledged that in addition to knowledge about AS and ASDs, it is essential to keep the individual child or young person at the forefront when planning interventions. Professionals and parents need to read the child or young person first and then the literature and recognise the differences between individuals with AS and determine what each individual child or young person actually needs. Then decisions can be made on how to address these and how to check out the response of the child or young person on a regular basis, which will include gaining their views. Good practice is that which recognises that '*one size does not fit all*' and there is a need to offer a range of options to families and children and young people with AS.

2.19.4.6 Department of Education (2005): Evaluating Provision for ASDs in Schools

This publication is to be used in conjunction with the CD Rom and DVD which were jointly produced by the Department of Education, the Education and Training Inspectorate (ETI), the Department for Education and Science and the Irish Society for Autism in the Republic of Ireland.

It is a very useful document and set of resources on the education of children with ASDs. There is one potential problem, however, in relation to children and young people with AS, as within the report, autism is used as a shorthand for all ASDs including AS, although it does not state this explicitly. So children with AS might not be seen by some professionals and parents as being covered by the Guidance. In fact, the term AS is not used anywhere in the document and yet much of its content is very relevant and useful.

The underlying values and principles are that:

- Children and young people with autism are children and young people first;
- Children and young people with autism have a right of access to education services that best suit their needs; and
- Learners with autism have a right to a programme designed to meet their unique needs and provide access to the curriculum of their peers.

The guidance further states that teachers, allied professionals and learning assistants should have an appropriate knowledge of:

- Autism;
- The holistic needs of the child;
- The impact of the child’s autism on his/her learning; and
- The impact of the child’s autism on his/her ability to interact/socialize.

Schools are asked to strive to ensure that the above principles underpin their work to promote best practice for children with autism.

The Guidance is set out in the form of standards or statements which specify the nature of the difficulties experienced by children with ASD. For example the first statement is:

Children with autism find too much stimuli difficult to cope with: once under stress they struggle to calm down. They prefer predictability and familiar surroundings and benefit from visual cues within the classroom and school.

Then below each statement is a grid with four headings:

Performance indicator	How the school might be modified
Performance assessment	Questions the sensory and visual environment
Performance outcome	How well is the school meeting this standard
Grade	Staff can rate how well the school is meeting this standard

This document enables schools to carry out their own assessment on how able they are to meet the specific needs of children with ASD. Schools are encouraged to consider the development of an autism action plan which should indicate:

- *The current capacity* of the school to meet the needs of children with autism;
- *The action underway* to ensure progress and improvement; and
- *The goals the school aspires to achieve* over a period of time.

It is suggested that the first step for a school is to audit its provision using the standards as benchmarks and to produce an action plan. It is suggested that support from the Autism Advisory Service is sought and the latter should provide training in promoting autism awareness.

It is acknowledged within the Guidance produced by the Department of Education that '*the introduction and development of autism provision standards will take time to achieve in Northern Ireland*' (p.18).

2.19.4.7 Autistic Spectrum Disorders: A Guide to Classroom Practice (Department of Education, 2003)

The Department of Education produced this guidance in 2003, following the Task Group Report which identified the need to produce some guidance for schools. This guidance was written by an Autism working group which had representatives from each of the five ELBs and the ETI.

It is designed for teachers and classroom assistants and covers different aspects of ASD, giving key teaching points and publications at the end of each section. Page 11 of the Guidance gives suggestions on the role of the classroom assistant.

2.20 Role of the voluntary organizations in developing services for individuals with AS

For many disabilities and conditions, the catalyst for service development in many countries has been the early efforts of parents and relatives who have grouped together as volunteers, and this was the case with autism too. In Northern Ireland, a number of voluntary organizations have played a pivotal role in developing awareness and expertise and in fund-raising and lobbying. There are four main organizations currently working in Northern Ireland – Autism Northern Ireland (Autism NI, formerly known as PAPA (Parents and Professionals and Autism)) which has been established for over 15 years, Autism Initiatives, Asperger's Network which has been running for about 4 years and the National Autistic Society based in England, which also has branches in Northern Ireland. Their work is included in this Review.

2.21 Educational needs of children and young people with Asperger syndrome

The impact of the triad of impairments on a child or young person's level of functioning and adaptation will vary enormously and will mirror variations within the general population as a whole. The prime educational need of the individual with AS is that the adults in a position of responsibility should have a clear understanding of Asperger syndrome and demonstrate this understanding by means of delivering appropriate and relevant learning experiences (Attwood, 1997; Myles, 2001; Kluth, 2003; Cumine, Leach and Stevenson, 1998; Jordan, 1999; Jones, 2002).

Acknowledgement of individual differences needs to be made, and the ways in which these differences are manifest are covered well by the literature, including plenty of anecdotal evidence for when adult understanding and accommodation was lacking. The biographies of those with AS and of parents have contributed much to our insight into the effects of AS on the individual (Jackson, L. 2002; Jackson, N, 2002, Sainsbury, 2000; Lawson, 2000; Segar, 1997).

Other writers have written about the educational needs of those with AS and strategies to address these (Hesmondhalgh and Breakey, 2001; Rigg, 2004; Department of Education, 2000). These include having clear strategies; explanation

of lesson content; expectations of acceptable behaviours; levels of teacher confidence; explicit steps for lessons; warning of changes; overt organisational strategies; achievable targets and meaningful rewards. These strategies, coupled with staff understanding and clear ideas on proactive behaviour management are now recognized good practice. Myles (2001) also believes in having clear room layouts and tasks; visual clarity (as in the TEACCH approach); adequate and personalised space; signals, cues and maps as well as an area to retreat to when things get too much. Changes in how the curriculum is delivered are often necessary and a very useful curriculum document has been produced specifically for children with ASD in secondary schools by the North West Regional Partnership in England (DfES, 2003). This raises the awareness of staff about the likely issues for a pupil with ASD, including their strengths, in all the major subject areas (e.g. Science, Maths, History, IT, Art and Design, PE).

Typical stressors are identified by Attwood (1998), and include a reduced ability to learn from mistakes, and a fear of failure, criticism or imperfection. This is not surprising given how frequently children and young people with AS are criticized by adults and peers. Mitchell (2005) points out the difficulties associated with mastering a two- or three-week timetable that exists in many secondary schools, and Jackson, L (2002) tells of the problems in activities such as team games, homework and different learning styles, as many with AS are predominantly visual learners. Learning styles of people on the spectrum are detailed in Plimley and Bowen (2006a). The additional disorders of hyperlexia; dyslexia; dyscalcula; dyspraxia may also affect the performance of the individual with AS in school (Attwood, 1998). Bellini's study (2004) of young people with ASD also highlights the increased incidence of anxiety and depression which may also need to be directly addressed in the school setting.

2.22 Educational interventions

The review of research evidence on educational interventions by Jordan, Jones and Murray (1998) shows that there are few robust research studies that have demonstrated the effectiveness of educational interventions that are currently in use in schools and centres. Most research has been done by the founders of the intervention, using small heterogeneous samples and few having a comparison

group. Meta-analyses have been conducted to identify the components that interventions, which appear to be successful, have in common, and a consensus is developing on the features of effective interventions (Dawson and Osterling, 1997). What is also clear is that most children and young people with AS will need a number of different interventions to address their needs, not just one, and that a particular intervention will not suit or be appropriate to ALL children and young people with AS or ASD (Jones, 2006). At the moment, practitioners and parents can be guided by their own judgement and knowledge of the child or young person and ask sensible questions about interventions which exist.

Given below are details and references to interventions which are most commonly used in UK schools and centres, and themed under the aspects of development or functioning they are designed to address.

2.22.1 Social understanding and development

Social Stories and Comic Strip Conversations (Gray, 1994; 1998)

The desire for contact without understanding the social rules can lead to:

- Misunderstanding of social cues from other people;
- Misunderstanding by others (e.g. viewed as sexual, aggressive);
- Vulnerability (e.g. teasing, bullying, exploitation); and
- Apparent lack of remorse.

A number of interventions have been designed to help develop the social understanding of children and young people with ASD and to give them strategies for social situations. These include Social Stories and Comic Strip Conversations devised by Carol Gray (Gray, 1994) to help pupils with AS understand and manage certain social situations. She suggests that a ratio of certain types of sentences should be used in the story, which can then act as a script and a prompt to remind the person what is needed in a certain situation and how they need to respond.

There have been a number of published papers reporting on their success (e.g. Chalk, 2003; Erangey, 2001; Rowe, 1999). Social stories involve giving information about the perspective of others, and clear, directive statements on what the child or young person should try to do. Children and young people with AS and their parents can and should be involved in creating these. Comic strip conversations are similar and use elements of a social story, but use line drawings or cartoons to convey the social messages.

Circle of Friends

Staff and parents often have to be social engineers to support the children and young people with AS and their peers and siblings. Those with AS may not be able to form a friendship without help, and other children may be confused by the child or young person and find it difficult to know how to engage him or her. The strategy known as Circle of Friends has been used successfully, where staff or parents create a group of friends for both work and play within and outside of school hours. These have been successfully used by staff in both mainstream and special settings (Whitaker, Barratt, Joy, Potter and Thomas, 1998). A circle usually consists of 6-8 volunteers who meet on a regular basis with the 'focus child' and an adult. The child or young person with AS discuss how they might like to be included in work and play and the issues arising from this, and so develop their appreciation of other people's perspective. The focus should move from the child with AS and become a circle of support for all. Such circles of support can be also be used to support Person-centred Planning exercises and open the dialogue between carers, agencies and the individual with AS (Gold, 1999; Brock 2003).

Buddy Systems

Many schools have introduced buddy systems for children and young people with AS who want a friend or partner for work or play. This may be done on a rota basis, and may involve same-age peers or older children. They may operate only at break-times or be used within lessons too (Mastralengo, 2005; Myles, 1998).

Peer Mentoring

Children and young people with AS are often more skilled in some areas than their same-age peers. They can therefore be asked to help and support other children, and this has the dual benefit of helping the child as well as boosting the self-esteem of the child or young person with AS. Strengths in subjects such as maths, reading and IT abilities as well as leisure pursuits (e.g. chess, Game-boys, special subject collections) may well fulfil this mentoring role (Szatmari, 2004).

Social Use of Language Programme (SULP) (Rinaldi, 1993)

SULP (Rinaldi, 1993) targets the pragmatics of language and communication which is a difficulty for children and young people with AS. It makes use of strong visual and graphic stimuli and deals with age appropriate issues and everyday situations. It provides opportunities to practise new skills and concepts via motivating activities and enjoyable tasks.

2.22.2 Transitions

A number of resources are now available to support transitions in schools from task to task, class to class and school to school (Broderick and Mason-Williams, 2005; Kluth, 2003; Myles, 2001). A range of ideas has been put forward to help the child with AS understand and function in a new school environment. These include:

- Virtual tours of the new school captured on CD Rom (Cook and Stowe, 2003);
- A clear visual map of the school, lists of teacher names and room numbers (Myles, 2001);
- Incorporating timetables and room allocations into personal computers or filofaxes for use throughout the school;

- Using themes for behaviour expectations (Harpur, Lawlor and Fitzgerald, 2006); and
- Having a 'travel card' with lesson reminders and a report by each teacher (Myles, 2001).

For children and young people with AS who may be in need of more intensive counselling support, the ideas of Wilkinson (2005) and Barry et al. (2003) are ways in which outside agencies may support inclusion and transition.

Finally, the idea of Cumine, Leach and Stevenson (1998) of using an 'Asperger lens' through which to view the perspective of children and young people with AS has proved very useful. This helps school staff to appreciate how children and young people with AS experience and perceive the world differently, leading to what may seem bizarre responses, but which are logical to the person with AS.

2.22.3 TEACCH approach (*Treatment and Education of Autistic and Communications Handicapped Children*) (Schopler and Mesibov, 1993)

This approach is often called a compensatory approach as it is designed to create environments within which children and young people and adults with ASD can be relaxed and work effectively and successfully. It also teaches skills, and makes communication clear. The two key elements are structure (leading to predictability), and visual information. It was developed in North Carolina in the US over 30 years ago and uses the strengths and emerging skills of the individual, presenting information on educational and everyday tasks in a visually clear and logical way. It suggests that information should be given about what is to happen, where it is to happen, the sequence of activities or stages within a session, and instructions on how to do each task within that. TEACCH is used from the early years to adulthood and requires no specialist resources (Mesibov, Shea and Schopler, 2004; Mesibov and Howley, 2003; Wellman, 2005). Myles Smith (2001) and Kluth (2003) have used TEACCH to develop systems and structures within their teaching environments using colour coding; equipment storage spaces; labelling the function of areas; providing schedules of activities, and test reminders and homework procedures. Myles Smith

(2001) also suggests compartmentalised backpacks for those who find it hard to organise themselves.

2.23 Educational provision for children and young people with Asperger syndrome

The range of educational provision for children with AS in the UK is documented by Jones (2002) and ranges from full inclusion in the life and learning of a mainstream school to a 52-week per year residential school. The majority of children and young people with AS will be placed in mainstream schools, some of which will have a resource base for children and young people with AS or learning difficulties. There are a number of case studies published on the successes of unit or base provision within mainstream schools (Barratt & Thomas, 1999; Parker, 2000; McRobbie, 2005). Key factors which can have an impact on effective practice include good communication between staff in the main school and the unit/base; flexibility and willingness of staff to do their best for the child; and the creation of a 'safe haven' for social times and potential times of distress (e.g. break times, lunch times). The safe haven can be a designated room, or an area or space in a room in which the young person can engage in de-stressing activities. Hesmondhalgh and Breakey (2001) describe the setting up of a resource in a mainstream secondary school and identify issues arising in its first four years. Useful strategies discussed elsewhere in this Review are described in a later publication (Hesmondhalgh, 2006), where examples of successful inclusion are extended into adulthood. The levels of functioning of the individual with AS will have a large part to play in the provision required.

Attwood (1998) warns of the dangers of assuming that children and young people with AS and with good or excellent skills in one or two areas should and can be able to function at similar levels in other tasks, subjects and school life generally. Children and young people with AS often have very uneven profiles and it is misleading to use the term 'high functioning' in relation to this group as their high level skills are often confined to one or two areas while they have huge difficulties and low skills in other areas. The child or young person with AS may possess an encyclopaedic knowledge of rote facts, for example, especially about their special interests, and this may be deceptive in our assessment of their overall ability and potential.

Finally, ways in which the school staff can approach the effective inclusion of children with AS are dealt with comprehensively in the work of a number of authors (Jones, 2002; Jacobsen, 2005; Myles Smith, 2001; Kluth, 2003; Plimley & Bowen, 2006). The heart of inclusion is not about the adaptation of buildings or provision of additional support staff, but lies within the gift of the staff of the school and their attitudes and willingness to make accommodations.

2.23.1 Features of inclusive and AS-friendly environments

The Good Practice Guidance (DfES, 2002) for schools in England includes pointers that examine where local authorities and schools can influence the success of inclusion for pupils with ASDs. These include:

- Policies and procedures to support those with ASD;
- Availability of training for staff at all levels;
- Staff awareness of ASD;
- Accessibility of pupil information;
- Workable strategies and interventions;
- Empathy and support mechanisms for the individual; and
- Good preparation for transitions.

Although the Guidance pertains to schools within England, other countries have used this as a model and impetus to create their own standards.

The concept of autism-friendly features

For a number of years, those designing new schools and centres, or adapting old environments for children and adults with ASD have sought advice on decisions concerning paint colours, types of lighting, types of heating, use of natural light, and construction of basic resources/facilities. There is very little written about the topic. To design for people with ASD there are a number of principles that need to be considered which have been identified by Plimley, (2004).

2.23.2 New school and unit provision

Factors involved in setting up new provision, whether a new special school or a unit within the main school are discussed by Plimley and Bowen (2006a) and include:

- How close is the local community?
- What are the major road routes to the provision like?
- How close are emergency facilities?
- How close are mainstream schools?

In England, some authorities now have the policy of developing new special schools on the site of mainstream schools to make inclusion opportunities and reverse integration much easier logistically. There is a useful article by Bishop (2001) who explores the guiding principles that appear to encourage inclusion.

Plimley and Bowen (2006a) cover design factors in depth and look at issues, especially relating to sensory differences and ergonomic factors. Kluth (2003) deals with the within-school factors that make up an autism-friendly environment in addition to the attitudes and approaches of the school staff. Staff attitude and understanding of AS is referred to again and again by first person authors (Sainsbury, 2000; Jackson, L, 2002; Jackson, N. 2002). Regular in-service programmes on AS will help to alter attitudes.

The use of resources such as The Teacher's Toolkit on ASD produced by the Department of Education in partnership with Autism NI and Aurion (PAPA, 2003) can be very helpful. Recent local authority training in Wales has used the CD Rom in this toolkit to good effect with targeted mainstream schools, both as a training tool and then for teachers and support staff to use with their colleagues (Plimley and Bowen, 2006b).

2.24 Sexual relationships and sex education

Issues around sexuality and relationships for people with Asperger syndrome have only recently appeared in the literature (e.g. Henault, 2005; Lawson, 2004; Pukki, 2003). This may be because issues of sexuality and the sexual behaviours of children are under-represented in the literature generally, but also may be as a result of the view that people with disabilities cannot be sexual beings or that people with ASD do not have an interest in a sexual relationship with another person.

In a review of programmes for people with AS or HFA, Pukki (2003) found that the majority of resources available reveal little relating to positive relationships/sexual experiences, and frequently there are negative connotations around dependence, attachment or obsessions about others. The inference is that there is an inferior quality in their attempts to form relationships. She goes on to say that systematic instruction on subtle forms of sexuality and combining sexual signals into the general social repertoire is not seen as important in the education of people with AS. The deficits in the resources she reviewed were their vagueness and lack of attention to the increased vulnerability of people with AS.

Lynne Moxon (2004) who works with students with AS in a college of further education, believes that sexuality for individuals with ASDs can encompass a broad range of responses and has outlined a number of dimensions, including the moral, social, biological and psychological dimensions. These dimensions can form the basis of an appropriate personal, social, sexual health programme for individuals with AS. It is important, however, to create such a programme in the context of individual needs. This is endorsed by Lawson (2004) who feels that any programme should contain a highly structured methodology using concrete strategies and the same type

of learning tasks as any other experience. She argues that too little information and incomplete concepts can result in the person with ASD behaving in a socially embarrassing and unacceptable way. She cites the TEACCH programme (www.teacch.com) for sex education as a useful training example. Claire Bullock (2005) outlines a highly individualised teaching programme that helped a young man control a desire to touch teenage girls, dealing with his feelings and intrusive thoughts, and intervening in his need for tactile stimulation by providing alternatives.

2.25 Forms of support for children and young people with Asperger syndrome and their families out of school hours

There are a number of factors which make it difficult or less likely that children and young people with AS access activities out of school in the evening and at weekends. Late diagnosis may mean that they have not had appropriate, or any, support up to that point. Their problems may have been exacerbated. They may have become isolated and have concerns about leaving home to attend an unfamiliar setting. Previous negative experiences with children of their own age can make them understandably reluctant to join a group which involves same-age peers. Their difficulties in making friends mean that they often do not have access to the natural out-of-school support systems (e.g. invites to friend's houses). For some, co-ordination, social or sensory difficulties will prevent them from engaging in sport or team activities organised by the school/college or local services. In addition, it may not be safe for them to leave their home unsupervised (e.g. because of road safety issues, inability to use public transport, vulnerability to be exploited by others).

It is very important for children and young people with AS to have ways in which they can use their time constructively out of school hours. They need to have positive experiences with peers and adults, and opportunities to learn the skills that others develop naturally. Without guidance and opportunities for out-of-hours activities, they are likely to spend large amounts of time isolated immersed in their special interests, or be easily influenced by others and possibly led into trouble. High support needs or over-dependence on their family, places a burden on their parents and siblings and can put strain on the family to the extent where issues relating to the child or young

person dominate family life. There is also a serious risk of depression and related self-harm, especially in adolescence (Ghazuiddin, 2005).

Different forms of support exist including parent support groups, sibling support groups, and specialist social skills or social groups. Children and young people with AS might also attend other generic activities which link to their special interests (e.g. chess, bridge, ice skating, or trampolining). Short-term breaks for the children and young people with AS or holidays might be funded or arranged for the family in some areas.

2.26 Life beyond school

Many parents of children with ASD are concerned about their future beyond school and college. Currently in the UK, there is often a gap between the transition from children's to adult services for all individuals with SEN, including those with ASD, and there may be fewer services to meet their needs.

2.26.1 Careers advice

All young people with a Statement of Special Educational Needs at the age of 14 should have an interview with a Careers Adviser. This is a legal requirement of the assessment and Statementing procedure. As with many other professions, it may be that the person concerned has little knowledge of AS and so is not best placed to advise on this. Those with AS have very specific needs and are likely to be much better suited to courses and employment which are not socially demanding.

2.26.2 Further and Higher Education

The major problem for those who have left school is finding advice and support to pursue Further or Higher Education or in finding employment. Until recently there was little written on these topics to support parents, individuals with AS or teaching staff and potential employers. There are now a number of publications on these topics (see *Further Reading* lists). Martin has a special interest in Further and Higher Education, and has recently written a paper to guide those involved in Higher Education (Martin, 2006). In this she makes suggestions on how the student can be

best supported before starting in HE/FE, and then once s/he has started on the course. Some of the main points she makes are given in **Appendix 2**.

2.26.3 Outcomes in adulthood

Howlin (2000; 2003; 2004) has studied the lives of adults with ASD and AS for many years and has conducted several studies on outcome in terms of employment, relationships and living arrangements. She maintains that with increasing age, there are generally increases in verbal IQ, improvements in self-awareness and self-control, and a reduction in some of their difficulties. Their social understanding and communication skills improve and there is a decrease in obsessional behaviour. Special interests for some individuals become the basis for their careers (e.g. in maths, computing, engineering and architecture). Problems which do arise are often due to boredom, low self-esteem, isolation from their peer group, a continuation of their childhood behaviours which are not acceptable with age and the fact that their parents become less physically able to support them. Research has shown that for those with AS, extrinsic factors such as support networks, the environment and demands made may be just as important as intrinsic person factors (Lord and Venter, 1992).

Particular areas where adults with AS have a difficulty include making decisions, adapting to planned and unplanned change, being able to problem-solve, acquiring the practical skills needed for everyday tasks and the ability to multi-task. In addition, their parents may find it hard to take risks with their son or daughter who has always needed more supervision and attention than others of the same age. Lack of coordination between services in the move from child to adult services, and between Education, Health and Social Services, also means that the assessment of needs and delivery of services is fragmented. In addition, there will be changes to financial allowances and entitlements.

In order to meet their needs, it is necessary for transitions to be carefully planned well in advance, in consultation with the individual with AS. They need to be given plenty of opportunities to discuss plans and their worries, and to have time to consider the options available, with opportunities to have 'tasters' of each of the options. When moving into Further or Higher Education or into employment, it is

important to consider all the skills and understandings required the whole time in these new environments, particularly the social demands. Often those adults who talk about their work say that it is the office politics that cause them the most difficulty, not the tasks set. There are issues about the work as well, however, in terms of setting priorities, working for more than one person and a desire to finish one task before starting another or not wanting to leave the workplace until all the work is done. A young adult with ASD working at Sainsbury's said he did not want to take the four weeks holiday to which he was entitled; he wanted to continue working (Hesmondhalgh, personal communication). This was solved by creating a holiday timetable for him setting out what he could do instead of going to work.

In adult services, Howlin (2003) has reported that psychiatrists often do not know how to recognize AS and may misinterpret the behaviours observed and reported, giving an incorrect diagnosis and treatment (e.g. for psychosis or obsessional compulsive disorder). The media, especially TV and newspapers, reports at times on the violent crimes committed and may incorrectly suggest that the person has AS without checking this out. This can lead to fear in families who have sons and daughters with AS and amongst their friends and relatives. In fact, a study by Ghazuddin (1991) which reviewed reports on 132 people with AS showed that only three had a clear history of violent behaviour which was lower than the 7% of typical young people aged 20 to 24 years who commit violent crimes in the US.

2.27 Staff training needs in Asperger syndrome

Most students with Asperger syndrome (AS) receive their education in mainstream classrooms, and there is a need to address the complexities of their difficulties to ensure they are properly supported. Many teachers have limited experience and training in working with children with special needs (Myles & Simpson 2002). Yet there is evidence to suggest that professionals who come into contact with these pupils need adequate training and the knowledge to draw upon methods and programmes that are adapted to the students' needs (Education Training Inspectorate, 2000; Task Group Report, 2001). In the UK, the DfES Good Practice Guidance (DfES, 2002) and West Midlands Regional SEN Partnership report on ASD (English and Essex, 2001), for example, highlight the fact that a good practice

protocol needs to state the importance of increasing awareness of ASDs, and of working towards an environment where people understand the nature of ASDs and are accepting toward individuals with ASDs. These guidelines also emphasise the need for specialist training that covers the breadth of the spectrum and should continue post-qualification as well. Jordan and Howlin (2004) stress that an important component of this is the need to train people who provide supporting roles. This is backed by Elliot's (2004) research that focuses on the need for anyone in a supporting role to have specific training for supporting pupils with ASD.

Research has also found that parents can be effective in teaching and maintaining skills and studies, and have highlighted the need for greater parental involvement in interventions (Di Pip-Hoy & Jitendra, 2004). Some research studies highlight parents' positive impact on children's learning (Eccles & Harold, 1993; Spann et al 2003) and show that parental involvement leads to benefits for children with SEN. This includes greater generalisation and maintenance of treatment gains (Koegel et al., 1991). Whilst researching outreach provision for pupils with ASD, Glashan et al (2004) found a positive relationship between parents' knowledge and involvement in school, and the success of the placement for children. Indeed, the lack of recognition received by parents has been considered to be a barrier to inclusion (Clements, 2004). Recent research highlights that parents and carers of disabled children wish to have their views heard (Lewis, Disability Rights Commission Report, Phase 1, 2006). Spann et al. (2003) indicate that despite much research showing the benefits of parental involvement in education, very few parents have any involvement in developing objectives, interventions or methods of evaluation. Parent involvement is therefore an important component for programmes designed to improve educational outcomes, and it is recognised that ongoing parent and teacher collaboration is an essential foundational element in the development and implementation of intervention programmes (Myles and Simpson, 2001; Safran & Safran, 2001).

In relation to Northern Ireland, training issues have received attention in recent years. The Northern Ireland Task Group on Autism (2001) highlights that there are likely to be increasing numbers of pupils with ASD coming through the school system as assessment and diagnostic practice is enhanced. The report identifies the importance of education in improving quality of life and of understanding these pupils,

and concludes that there has been rapid improvement in provision over the last few years. However, parents, voluntary bodies and statutory bodies alike recognise that there is still much progress to be made before it will be possible to say that all children and young people with ASD are being identified and that their needs are being fully met. There is, in particular, a demand for prompt access to diagnostic services at an early age and these services should be followed immediately by effective home- and school-based intervention. The report highlights three key priorities:

- Access to multi-agency and multi-disciplinary diagnostic and assessment services;
- Training for parents of, and people who work with, children and young people with ASD; and
- The need for school-based and home-based educational and therapeutic provision.

The report recognises that intervention needs to be based on comprehensive diagnostic assessment and stresses the importance of speech and language services. The Task Group considers that it is crucial to include social skills training in all intervention programmes for children and young people with ASD. It also emphasises the need to offer structured programmes, to reduce anxiety and stress and to recognise sensory difficulties.

The conclusions from the Task Group Report follow on from the survey of AS conducted by the ETI (Education Training Inspectorate) in Northern Ireland. This survey covered pupils with AS in primary and secondary schools between 1999 and 2000. In relation to training needs, the survey identified the need of staff for advice about Asperger syndrome and the implications for teaching. This includes specific advice on the individual child's needs, about how to deal with behaviour and emotional problems and finally advice about how to support parents and help them access support from other agencies. Staff expressed a desire to have access to expert guidance for reassurance and ongoing training. The survey identified the need

for in-service training and suggested that a booklet with essential information and practical approaches in the classroom would be useful. Teachers also highlighted that they would welcome the opportunity to meet with other teachers who were working with pupils with AS. The area Board's Curriculum and Advisory Service (CASS) was mentioned as supportive, but difficult to access because of the constant pressure from schools for CASS support. The schools reported that the area boards were offering more courses about autism in the last two years, and many had applied for places. In-service training was viewed as highly sporadic, short-term and not given high priority. The survey recommended a programme of in-service training to support teachers and classroom assistants.

2.28 Support for families with a child or young person with Asperger syndrome

There is much literature on the effects of AS on the family. Research studies primarily focus on the stress on families, and a number of research studies emphasise the frustration of parents with services and support or the lack of it. Some research has found that families with a child with ASD have higher levels of stress than families of children with other SEN (Dumas et al., 1991; Preece, 2000; Weiss, 2002). Gray (1994) highlights that this is, in part, related to the fact that families recognise symptoms and then have to persuade others, including medical personnel, of their existence. Delay in obtaining a diagnosis therefore causes additional stress to families (Quine and Pahl, 1997).

Most research on families who have a child with an ASD focuses on diagnosis, services and the family's ability to cope. Hutton and Caron (2005) highlight the unique experiences and challenges of families with ASD. Howlin and Moore (1997) describe how many parents have serious concerns at an early age, yet only 10% obtained diagnosis when they first sought advice. More than a third were told not to worry or to return if problems persisted. Piper and Howlin (1999) also found that the earlier the age of diagnosis, the greater parental satisfaction. Confusion about diagnosis also has broader impact as it can lead to isolation from family and friends.

Many families have indicated that they would benefit from better respite or short-term breaks. There is a need for a flexible mix of services that provide support and routine in school holidays and ongoing support during the year. Children and young people with AS often cannot access services because they do not have a 'learning disability.' Activities which are offered to children with a learning disability, are often not suitable for those with AS. Another factor that contributes towards stress is the fact that families interact with many different agencies.

Recent research has also highlighted the positive resources that families can offer. The Hero's story examined thirty-three self-published websites on the internet. All these websites were constructed and written by parents of children with ASDs. The study showed that the internet allows stressed parents to forge ties and overcome isolation.

It describes how parents go through a process of coping and come out the other side wanting to help other parents. The emphasis is on gaining knowledge and learning, embarking on a path of empowerment and coping with adversity.

SECTION 3: DATA

Numbers of children and young people with Asperger syndrome within Northern Ireland

3.1 Introduction

It was possible to examine the numbers of children and young people expected with Asperger syndrome and the numbers of children and young people actually known by the schools and colleges in each of the five Education and Library Boards. This gives information on the diagnostic practice and identification rates in each Education Board. In addition, parents, children and young people and schools from all five Boards completed questionnaires and where appropriate, these responses were analysed on a regional basis. The latter data should be regarded as a sample of what is happening in the five Boards and not as a full and comprehensive picture of all that is in place. It was not possible within six months to identify and record all the services and supports for children and young people and their families in each area. Other reports, policy documents and publications have been written by professionals and others working in Northern Ireland and these are a very valuable supplement to this Review. Some of this literature has been reviewed in Section 2 and there are further references given at the end of this report.

Note

The main findings have been presented in summary form in the Executive Summary of this report and appear in a different order here. The number given to the Finding in the Executive Summary is put alongside the relevant finding in this section of the report.

3.2 Data on children and young people with Asperger syndrome collected by the Department of Education in Northern Ireland

(FINDING 2 in the Executive Summary)

The Department of Education collects data on the numbers of children with Asperger syndrome on the roll of mainstream and special schools. It has produced guidance entitled '*Guidance for schools: recording children with SEN*'. Categories within this Guidance are for use by ELBs from September 2005, and by schools for inclusion in the September 2006 Census.

The Guidance was developed to produce standard data on SEN across Northern Ireland on children for whom educational provision was different from or additional to, that usually made for children of a similar age. ALL children on the Special Needs Register of a school are to be recorded (i.e. those from Assessment Stages 1 to 5 as specified in the Code of Practice). This would appear to be a very useful database to use for planning provision and monitoring practice.

The purpose of the records is to:

- Study trends;
- Aid planning and policy;
- Monitor outcomes;
- Identify current and future funding needs; and
- Respond more easily to requests for SEN related information.

Seven main areas of SEN have been defined, and each of these have further sub-categories within. The seven areas and their subgroups are:

1 Cognitive and learning

Dyslexia, dyscalculia, dyspraxia, mild learning difficulties, moderate learning difficulties, severe learning difficulties, profound and multiple learning difficulties, unspecified;

2 Social, emotional and behavioural

Social and behavioural difficulties, attention deficit disorder, attention deficit hyperactivity disorder;

3 Communication and interaction

Speech and language difficulties, autism, Aspergers (sic);

4 Sensory

Severe or profound hearing loss, mild or moderate hearing loss, blind, partially sighted, multi-sensory impairment;

5 Physical

Cerebral palsy, spina bifida and/or hydrocephalus, muscular dystrophy, significant accidental injury, other;

6 Medical conditions/syndromes

Epilepsy, asthma, diabetes, anaphylaxis, Down, other medical conditions or syndromes, interaction of complex medical needs, mental health issues; and

7 Other

Clearly, many children with autism and AS (and children with other SEN) will have difficulties in more than one of these categories. Respondents have therefore to judge which is the primary category. There is the possibility for confusion in that AS might also fit under category 6, as it is a syndrome. Respondents are given help in deciding which category to use by the subgroups which are suggested under each. Autism and Asperger syndrome comes under the heading of 'Communication and interaction' and a brief definition is given of each, as follows:

Autism (AUT)

'It is recognized that autism covers a wide spectrum but it should be noted that pupils who are diagnosed with Aspergers (sic) should be recorded in the next category.'

Pupils with autism will have difficulty:

- *Understanding and using non-verbal and verbal communication;*
- *Understanding social behaviour, which affects their ability to interact with children and adults; and*
- *Thinking and behaving flexibly, which may show in restricted, obsessional or repetitive activities.*

Pupils with autism cover the full range of ability and the severity of their impairment varies widely. Some pupils also have learning disabilities or other difficulties, making diagnosis difficult.

Pupils with autism may have difficulty in understanding the communication of others and in developing effective communication themselves. Many are delayed in learning to speak, and some never develop meaningful speech.

Pupils find it difficult to understand the social behaviour of others. They are literal thinkers and fail to understand the social context. They can experience high levels of stress and anxiety in settings that do not meet their needs, or when routines are changed. This can lead to inappropriate behaviour.

Some pupils with autism have a different perception of sounds, sights, smell, touch and taste, and this affects their response to these sensations. They may have unusual sleep and behaviour patterns.

Young pupils may not play with toys in a conventional and imaginative way but instead use toys rigidly or repetitively. They find it hard to generalize skills and have difficulty adapting to new situations and often prefer routine’.

Aspergers (ASP)

'Pupils with Asperger's syndrome exhibit similar difficulties to those described under autism. These pupils share the same triad of impairments but have higher intellectual abilities and their language development is different from the majority of pupils with autism. They may not have any clinically significant delay in language or cognitive development.

Pupils with this disorder may have impairment in social interactions and communication skills. They may also develop stereotyped behaviour, interests or activities' (pages 12-13).

Writing short descriptors of complex conditions is a challenge. This definition of Asperger syndrome is not entirely accurate if compared to the current diagnostic criteria, and does not help respondents as much as it might to differentiate between children with autism and Asperger syndrome (see **Appendix 1** for the diagnostic criteria for Asperger syndrome and autism).

Respondents are asked to record a child's PRIMARY need under one of these seven headings and, if appropriate, their SECONDARY need.

3.2.1 Data on the numbers of children and young people with AS attending schools and colleges in 2006

(FINDING 14 in Executive Summary)

There has been a very large increase (five fold) in the number of pupils recorded as having AS by the Department of Education over the years 1999 to 2006 when the data are compared. It may be that the 2006 figures included pupils at all stages of the Code of Practice. The 1999 survey was not clear on this, stating that it took figures of those pupils who were included in the statutory assessment process. The figures for 2006 are much closer to the expected rate of 36/10,000, and in the South Eastern Board, are over this. It may be that some children who would have been diagnosed as having autism by other clinicians might have been diagnosed as having Asperger syndrome. As the literature shows, diagnosis of conditions within the spectrum is as yet not a very exact science and so this might happen. The Department of Education

gathers data separately on Autism and Asperger syndrome, so the figures for pupils with autism have also been given by Education Library Board (see Table 3).

What is also clear is that there is still significant variation (from 18/10,000 to 42/10,000) between the five Boards in terms of rates of identification. It may be that in some cases, there is over-identification and in others, it appears there are still children with AS being missed.

3.2.1.1 Data for the West Midlands in England for 2006

The DfES in England does not collect separate figures for children with AS, collecting combined information on those with an ASD, which includes pupils with Asperger syndrome, who have a Statement or who are at School Action Plus on the Code of Practice (i.e. the equivalent of Stages 3 to 5 in Northern Ireland).

The data on the number of children with ASD for all authorities in the West Midlands for January 2006 are presented in Table 3 to show the variation in identification rates in different authorities in England, to illustrate that the five ELBs in Northern Ireland are not unusual in having very different rates of identification within their schools. There is an added complication to data from schools, as the figures are based on children with ASD who have a Statement or who are on Stage 3 or higher on the Code of Practice. It is known that authorities and schools have different percentages of children with SEN with a Statement, and that to some degree, Statements depend on how good the school and authority is at meeting needs. That is, the better the school at differentiating the teaching and the curriculum, the fewer children might be in need of additional resources and a Statement. These figures will not therefore include a child or young person with a diagnosis of AS who is managing well in school and is not on Stages 3 to 5 of the Special Needs Register. It is hard to know how many children and young people with a diagnosis of AS actually do manage school life quite well and who have no need of support. It must be borne in mind when reading the literature on AS that the focus will inevitably be on those who come to the attention of services, and the picture given is therefore skewed to those who have identified problems.

Table 3: Data on pupils with an ASD for each of the fourteen West Midland Education Authorities in 2006

Education Authority	Pupil Population DfEE Jan 1999 4 to 18 years	Estimated Primary School Population	Total ASD in 2006 Primary Schools DfEE Data	Rate of ASD per 10,000
Birmingham	188,166	94,000	382	40
Staffordshire	138,548	69,000	273	40
Worcestershire	90,994	45,000	134	30
Warwickshire	83,158	41,000	165	40
Coventry	54,137	27,000	168	62
Sandwell	52,827	26,000	61	23
Walsall	51,112	25,000	84	33
Dudley	51,535	25,000	70	28
Shropshire	44,888	22,000	96	44
Wolverhampton.	45,189	22,000	28	13
Solihull	40,917	20,000	83	41
Stoke	40,136	20,000	39	20
Telford & Wrekin	27,943	13,000	66	50
Hereford	25,994	12,000	33	29
TOTALS	935,544	461,000	1,682	36

Source: DfES Data 2006

Table 4: Number of pupils identified with autism and AS in mainstream primary and secondary schools in 2006 in each of the five Education and Library Boards.

Board	Pupil Population	Number with Autism	Number with AS	Total Autism + AS	Rate per 10,000 Autism	Rate per 10,000 AS
Southern	72,165	210	213	423	29	30
North Eastern	71,284	148	124	272	20	18
South Eastern	64,725	214	277	491	33	42
Western	58,747	79	137	216	14	23
Belfast	56,865	43	188	231	8	33
TOTALS	323,786	694	939	1633	21	29

Table 5: Number of pupils Identified with autism and AS in mainstream primary and secondary schools in 1999 and 2006 in each of the five Education and Library Boards

1999 Data				2006 Data		
Board	Pupil Population	Number with AS	Rate per 10,000	Pupil Population	Number with AS	Rate per 10,000
Belfast	56,865*	39	7	56,865	188 (204)	33
Western	58,747*	33	6	58,747	137 (211)	23
Southern	72,165*	28	4	72,165	213 (259)	30
North Eastern	65,000	4	0.6	71,284	124 (256)	18
South Eastern	66,785	56	9	64,725	277 (233)	42
TOTALS	319,562	160	5	323,786	939 (1166)	29

*2006 figures used

Note: The figures in brackets the numbers expected if the prevalence rate for AS of 36/10,000 is taken.

1999 data

All but one ELB (North Eastern) has fewer pupils identified with autism than with Asperger syndrome, and that is what would be expected from epidemiological studies, that is, there are more people with AS than with autism. Again, there is

marked variation between the Boards in the rates of identification of autism. The South Eastern Board has identified more children with autism than any other Board (as it did for Asperger syndrome), so it appears that professionals in this area are more able or willing to give the diagnosis than in other Board areas, or it is possible that some professionals may 'over diagnose' the condition, that is, they use a very wide definition of AS and autism and so include children whom other diagnosticians might argue do not fulfil the diagnostic criteria. The BELB has the lowest rate in terms of the numbers diagnosed with autism. The exact reasons for the differences in rates between the Boards would be difficult to establish, but a detailed study of some of the children diagnosed might throw some light on why this might be.

3.2.2 Pupils with AS in primary and post-primary mainstream schools in Northern Ireland

This Review was focused on children and young people aged from 10 to 18 years. The Department of Education collates the figures separately for pupils in post-primary (secondary) from those in primary schools. Tables 6 and 7 show the numbers of pupils identified in both phases of education. There are two potential influences here. The first is that diagnostic services in the past are unlikely to have been as good as they are currently, so there will be fewer older pupils with AS in post-primary school, and a second factor which will have the opposite effect whereby children with AS are often not identified until they are older, and so more pupils with AS will be found in the post-primary schools.

When the ratios are calculated in relation to the total populations for each Board, the South Eastern Board has identified the most children and the Western Board the fewest. The reasons for these differences would be difficult to establish and would need a detailed study of some of the children and the diagnoses made.

Table 6: Numbers of children with Asperger syndrome and autism identified by **primary** schools in the DENI data collection 2006

Board	School popn. Yrs 1 to 7	Autism	Asperger syndrome	Total	Ratio ASD: total
Southern	38,535	176 (85)	125 (139)	301 (224)	128
North Eastern	38,292	127 (84)	84 (138)	211 (222)	181
South Eastern	36,241	192 (80)	166 (130)	358 (210)	101
Western	31,154	65 (69)	81 (112)	146 (181)	213
Belfast	25,724	37 (57)	125 (93)	162 (149)	156
Totals	169,946	597 (374)	581 (612)	1178 (986)	144

Note: The figures in brackets give the expected number of pupils, taking the 22/10,000 rate for autism and the 36/10,000 rate for Asperger syndrome.

Ratio: The lower the figure in the ratio column, the more pupils with AS or autism have been identified in that Board

Figure 3.

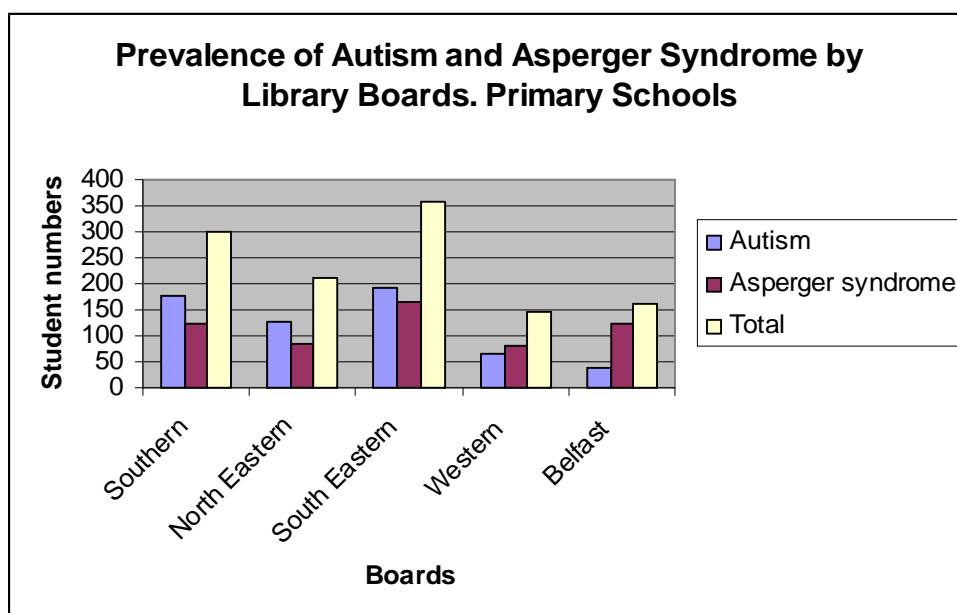


Table 7: Number of children with Asperger syndrome and autism identified by **post-primary schools** *(secondary) in the Department of Education data collection 2006

Board	School popn.	Autism Boys	Autism Girls	Autism TOTAL	AS Boys	AS Girls	Asperger TOTAL	All TOTAL
Southern	33,630	30	4	34 (74)	777	111	88 (121)	122 (195)
North Eastern	32,992	20	1	21 (73)	340	6	40 (119)	61 (191)
Belfast	31,141	4	2	6 (69)	555	8	63 (112)	69 (181)
South Eastern	28,484	21	1	22 (63)	997	14	111 (103)	133 (165)
Western	27,593	12	2	14 (61)	449	7	56 (99)	70 (160)
Totals	151,840	87	10	97 (334)	3112	146	358 (547)	447 (881)

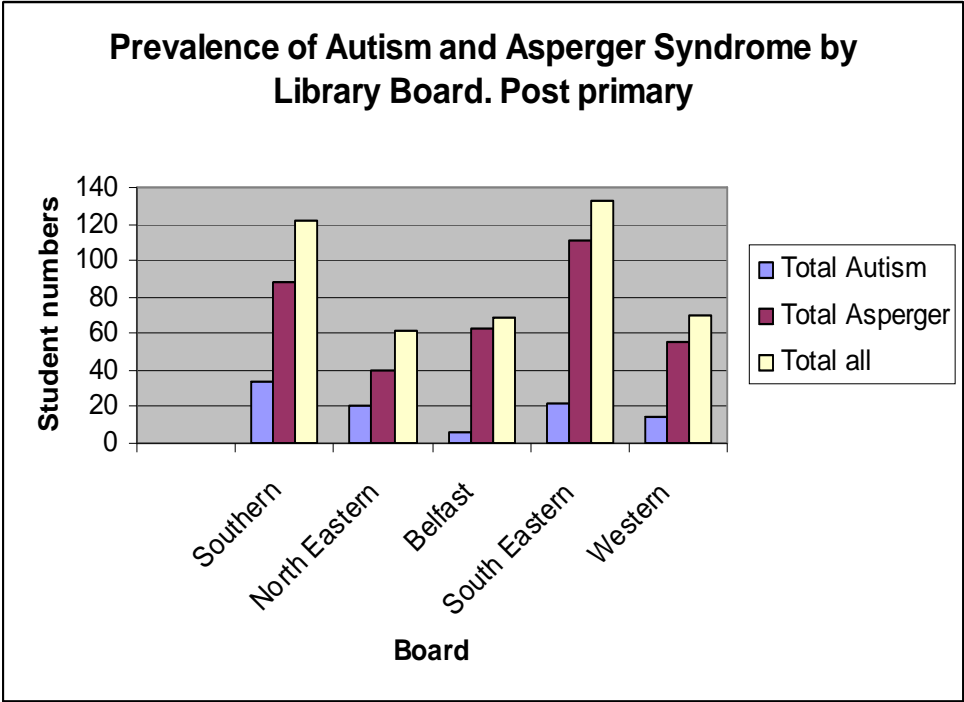
Note: the figures in brackets are the expected numbers if the rate of 22/10,000 is taken for Autism and 36/10,000 for Asperger syndrome.

3.2.3 Ratio of children with AS or autism to the total child population

(FINDING 15 in the Executive Summary)

The lower the figure, the more children with AS or autism have been identified. When the ratios are calculated for each Board at the secondary phase of education, then the ratios are 540 (NE); 451 (B); 394 (W); 275 (S) and 214 for the SE, with an average of 339 for all the Boards taken together. So the SE Board has identified the most children and the North Eastern Board the fewest. These ratios show that fewer children with AS and autism are currently identified at the secondary phase, than in the primary phase of education. The ratios for the primary phase were 213 (W), 181 (NE), 156 (B), 128 (S) and 101 (SE), with a ratio of 144:1 for the total primary population.

Figure 4.



The numbers of pupils attending secondary schools are slightly less for each Board than those attending primary school and so the actual number of children identified with autism and AS is expected to be lower. The total secondary school population for three of the Boards is an average of 32,000 and for the South Eastern and Western Boards closer to 28,000 pupils. There are more children with AS identified in the primary schools than in the secondary schools in each one of the 5 ELBs, the total number in primary schools being 581 compared with just 358 in secondary schools. This reflects the increased awareness and diagnosis of pupils with AS and autism in recent years, whereby more children are being diagnosed and diagnosis is occurring at a younger age. These data have significant implications for secondary schools in the future as there will be many more children than currently identified who will need support.

In terms of the ratio of autism to AS, there are many more pupils identified as having Asperger syndrome (as compared to autism) by a ratio of 3.5 to 1. All the Boards have identified more pupils with AS than with autism.

For the post-primary data, the gender of the pupils is also given which is interesting to examine. Epidemiological studies show that there are many more males than females with autism (4:1) and Asperger syndrome (maybe 10:1) (MRC, 2001). This is reflected in the data for Northern Ireland. For the autism group, the ratio is 8:1 and for the AS group, the ratio is 6.5 to 1. These ratios are the reverse of what the literature suggests, as the number of females is generally lower in the Asperger group. More detailed analysis of the diagnoses given to individual children and the data on which schools are making these judgements would need to be made to explore the possible reasons for this.

3.2.4 Nursery-aged children

For nursery-aged children, as one might predict, there were more children diagnosed with autism than Asperger syndrome (see Table 8), as the latter is often not picked up until the primary years or later. In the primary schools, the totals for autism and AS were fairly similar, although in the secondary schools, there were many more children with AS than autism.

Table 8: Numbers of children with AS in nursery schools and classes in 2006

Nursery Schools Board	School population (FT and PT)	Autism	Asperger syndrome	Totals
South Eastern	1,871	26 (4)	1 (7)	27 (11)
Western	1,694	7 (4)	2 (6)	9 (10)
Southern	1,565	15 (3)	2 (6)	17 (9)
North Eastern	1,559	6 (3)	1 (6)	7 (9)
Belfast	1,360	5 (3)	8 (5)	13 (8)
Totals	8,049	59 (18)	14 (29)	73 (47)

Note: The figures in brackets give the expected numbers for autism if the prevalence rate of 22/10,000 is taken and for Asperger syndrome at a rate of 36/10,000.

3.2.5 Special schools and classes

Given that one of the diagnostic criteria for AS is that the child or young person has average or above-average intellectual ability, one would predict that most of these pupils will be placed in mainstream schools. However, data from special schools show that there are a total of 66 children and young people with AS attending special schools (see Table 9) and three of the parents who completed questionnaires had children in this sector. Smaller class sizes, knowledge of specific strategies and a smaller physical site and lay-out are advantages which these schools have, and can enable pupils who find mainstream schools too difficult to be more relaxed and educated effectively.

Table 9: Numbers of children with AS in special schools and classes in 2006

Board	Spec. sch. popn.	%age of school popn	Autism boys	Autism Girls	AS Boys	AS Girls	Total Boys	Total Girls	Total All
Southern	394	< 1	63	13	7	3	70	16	86 (2)
North East	1,010	1.3%	87	25	7	0	94	25	119 (6)
South East	1199	1.8%	167	38	8	0	175	38	213 (7)
Western	748	1.2%	73	12	5	2	78	14	92 (4)
Belfast	1,248	2.1%	85	16	30	4	115	20	135 (7)
Total	4,599	1.3%	475	104	57	9	532	113	645 (27)

Figure 5.

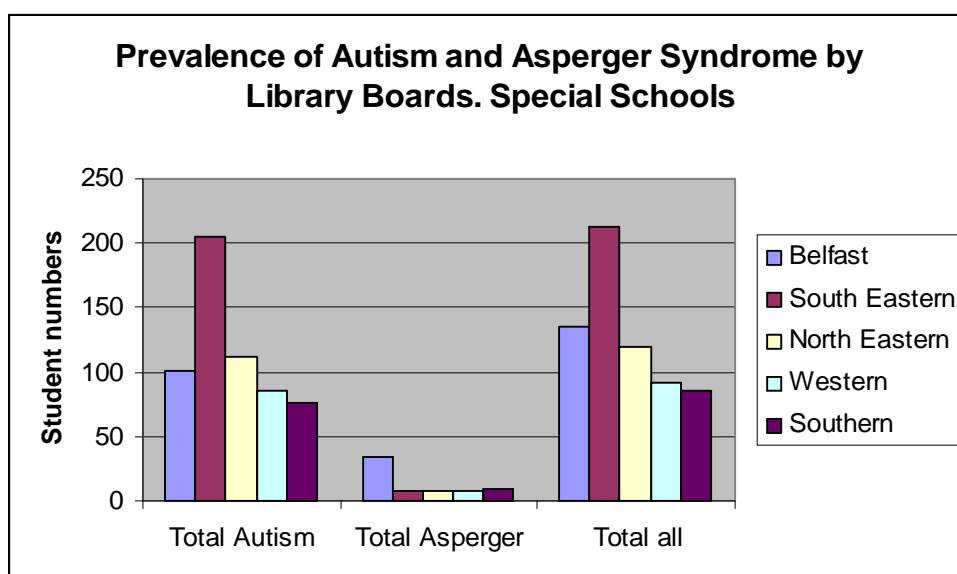


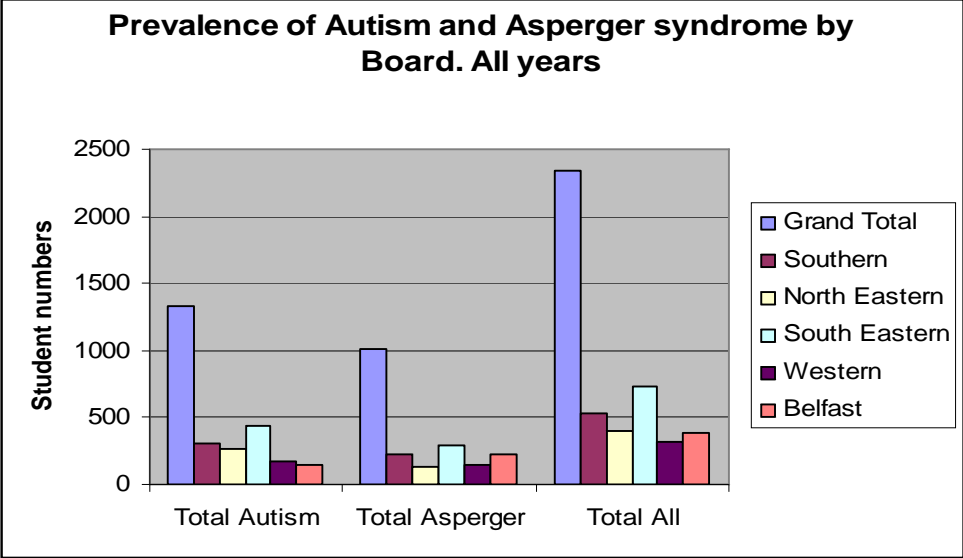
Table 10: Total number of children with AS in all schools, including nurseries, by Board in 2006

Board	Total Autism	Rate/ 10,000	Total Asperger	Rate/ 10,000	Total All	School Population
Southern	301	40	225	30	526	74,124
North Eastern	266	36	132	18	398	73,853
South Eastern	445	67	286	43	731	67,795
Western	171	28	146	24	317	61,189
Belfast	149	25	230	39	379	59,473
Grand Total	1,332	40	1,011	30	2,343	334,434

Table 10 shows that overall, and when child population figures are taken into account, the South Eastern Board has identified the greatest number of children with AS, at a rate of 43 per 10,000, and the North Eastern Board has identified the lowest number of children with this condition. A detailed study of individual case histories and diagnostic practice would need to be made to examine the possible reasons for the differences between the identification rates for each Board. It is likely that there are several factors

involved, including expertise of professionals, awareness of AS in schools and by parents, and ability to access and provide services.

Figure 6.



SECTION 4: VIEWS OF CHILDREN AND YOUNG PEOPLE WITH ASPERGER SYNDROME

The decision was made to present the data from the children and young people with AS first, as it is their needs that are the focus of the Review and that others are trying to address. In addition, it is only relatively recently that those in the statutory services in the UK and elsewhere have taken steps to consult more widely and effectively with children and young people on what needs to be provided and what their views are on how best this can be done. Gaining the perspective of those who have AS should not be just an add-on, but a key component of service design and delivery.

Following the data from the children and young people, is the data from parents and carers (Section 5), who are the major resource in their lives and whose views, again, are key to developing services which meet their needs. Asking parents what would make a difference, rather than fitting families into the services that are usually provided, is a key question.

Finally, data from schools and colleges (Section 6), health and social services (Section 7) and the voluntary sector (Section 8) are presented – last, but not least – as their contribution and drive is also paramount in providing high-quality services. There is very good practice to report on the work of practitioners and planners in all the statutory services and in the voluntary sector. There is still much to do, but there is evidence that some services have improved, and guidance exists to support the development of services for those with AS.

4.1 Data from the children and young people

Children and young people with AS are people first, and there are many other aspects which might be written about apart from their AS. (The same is true for the parents of children and young people with AS). Very often what can happen is that the AS is seen as the main and over-riding component of the children and young people and the family, and all else may be given little attention. It is important to acknowledge that children and young people with AS also have other needs and attributes, and varying personalities and characteristics. However, since the focus of this Review is on Asperger syndrome, AS is at the forefront of what is written.

4.1.1 Issues around giving the diagnosis of Asperger syndrome

Asperger syndrome is a condition which affects many areas of daily living, school, college and work. As with any condition, some children and young people with AS (both those who are diagnosed and those yet to be diagnosed), are more severely affected than others. For some children and young people, their AS will therefore play a smaller part in their life overall, but for others it will have a major impact. Those who have received a diagnosis of Asperger syndrome are likely to have specific needs which need to be addressed as these individuals have come to the attention of parents and professionals because they have difficulties with certain aspects of their lives. So staff in schools and colleges and other professionals need to take account of the needs arising from their AS. There are many adults and children with AS, though, who have not been diagnosed. For some of these individuals, there may be little benefit in having the diagnosis, but there will be others who would benefit. Systems for diagnosis need to be such that diagnosis is made early, and the needs arising recognised and addressed. For any child or young person, it is important to consider the pros and cons of making and sharing the diagnosis. Some of the advantages and disadvantages are discussed in a recent book edited by Dinah Murray (2006), which is an excellent resource for young people, parents and professionals alike.

It is always important with a child or young person to identify and maximise their strengths, skills and interests. For children and young people with AS, there will often be areas where they are more skilled and able than other children and young people of the same age. This knowledge can be used to raise their status in the eyes of peers. Strengths and interests can lead to good careers and/or to satisfying leisure pursuits and should be encouraged by all involved with the child or young person. What is also true is that children and young people with AS will find many everyday aspects in life, particularly the social areas, very hard to understand. They may be told several times a day that they have got it wrong, thus having a depressing impact on their self-esteem and feelings of self-worth. Some adults with AS say that is very helpful if other people tell them what they need to do in a given situation, as they will not necessarily know. This needs to be done in a sensitive, confidential and positive manner, focusing on what the child or young person should do, rather than telling

him/her what not to do and thus criticising them. In addition, it is important to check their understanding of the instruction given or to go first, and demonstrate what they have to do.

Data from the children and young people in the Review showed that some had positive expectations and views of themselves, but many were also well aware of the difficulties they had, particularly in understanding other people and making friends, and were often very conscious of the negative responses of other people towards them.

4.1.2 Data collection from children and young people with Asperger syndrome

A questionnaire was devised specifically for children and young people with AS to complete (see **Appendix 3**). These were given out in three main ways:

- Via the voluntary groups, Autism NI, Autism Initiatives and Asperger's Network
- From professionals who sent the questionnaires to families they knew
- Via the website set up by the review team

The questionnaires were given out by members of the different branches of the voluntary organisations and by those working in Health Boards. Figures were not kept on how many were sent out in total so that it is not possible to know how good the response rate was. Ten children completed the questionnaires whilst attending a group run by Asperger's Network and these were returned to the NICCY offices. In total, 35 children and young people with AS returned completed questionnaires to the review team (see Table 11). All but five of these young people completed the questionnaires in their own handwriting. For the five who did not, their parents wrote in their answers from dictation. Ten of these young people were also interviewed individually face-to-face by a member of the Review team so they could elaborate on their responses. The questionnaire was used as the interview tool. In the case of eight children, these interviews were arranged in school time at the offices of the educational Advisory Team, and in two cases, the interviews were held at the child's home. Their comments are included in the data presented in the sections below.

This sample is not representative of the total population of children and young people with AS living in Northern Ireland for a number of reasons:

- It was self-selecting and not a sample selected against specific criteria;
- It only reached those young people with a diagnosis of AS who were known to a service or an agency, or who had access to the internet;
- It did not include those children and young people who had a diagnosis of AS, but whose parents or professionals had not yet told them of this.

The responses of some of the children and young people had a positive feel throughout in the comments they wrote, and suggests that some were receiving good levels of appropriate support. Others made comments showing some significant concerns, although these often had positive comments too. A few questionnaires were almost entirely negative, where the child or young person felt that their current life and experiences were very hard, and they appeared angry and/or very unhappy.

Table 11: Gender and age of the children and young people who completed the questionnaires

Gender		Age in years		
Male	Female	10-12	13-15	16-18
29	6	10	10	15

4.1.3 Finding out about their diagnosis of Asperger syndrome

The children and young people were asked to state how long they had known about their diagnosis, and who had told them. Then they were asked to write down three facts about AS which they would tell another child, if asked; two things they felt were hard about having AS; and then to state whether there were any advantages to having AS.

4.1.4 Length of time they had known about their diagnosis of AS

Five of the 35 children did not know when they had been told about their diagnosis. For the others, 15 (50%) had been told by the age of 10 years (see Table 12). There was a tendency for the older children to have been told at an older age, perhaps reflecting the increased emphasis recently in the literature on the value of giving the diagnosis to the child him or herself. The majority (23) had been told about their diagnosis by their parents and eight young people had been informed by professionals.

Table 12: Age at which the child/young person was informed about their diagnosis

Age of child	Age when told	Number
Age group in years		
10-12 (n=7)	6	1
	7	1
	8	5
13-15 (n=10)	7	1
	9	4
	10	5
16-18 (n= 13)	11	4
	12	2
	13	2
	14	3
	15	2
Total		30

4.1.5 Three facts about Asperger syndrome

The children and young people were asked to write down three things they would tell another child about Asperger syndrome, if they were asked. Their responses have been grouped according to their age. Their statements were categorised in terms of whether they were positive, neutral or negative in content (see Table 13). There were almost twice as many negative statements as positive comments which is, perhaps, not surprising. The older children and young people also wrote more statements than the younger children, probably reflecting their increasing literacy skills. Most of the statements showed very good insight and understanding into how Asperger syndrome was defined, with none of the 35 children making a statement that was erroneous or mythical. This reflects well on the discussions that parents and others have had with the children and young people, as work with other groups of children and young people with AS has sometimes highlighted information about AS which was incorrect (Jones, 2002).

Table 13: Type of comments made by the children and young people in response to how they might describe Asperger syndrome to another child

Age group	Number of positive statements	Number of neutral statements	Number of negative statements	Totals
10-12	2	7	12	21
13-15	3	6	11	20
16-18	12	5	20	37
Total	17	18	43	78

4.1.6 Responses from children and young people in the 10 to 12 year age group (n=10)

Nine children made a total of twenty-one statements about AS. Six of the children wrote down three statements, as requested, and other children and young people wrote just one or two. One of the children and young people in the group did not write anything in response to the question. Seven statements were neutral, twelve were negative in content, and two were positive. Their descriptions are given below,

starting with the positive comments made, then the neutral and then the negative comments. Where a young person made more than one comment, these have been grouped together. Each new statement depicts a different child or young person, so where two or three statements are grouped together, this is the response of ONE child. Their spelling has been retained, unless it affected the meaning.

10 to 12 year-olds

Positive comments

Just one of the children in this age group wrote down a positive comment, as follows:

That they can be smarter than others

That they can be more playful.

Neutral comments

These comments were largely factual and focused on difference.

You think differently.

That they have a different personality

I'm different

It was a disease

I have it

It is also known as autism

Affects learning and behaviour

Negative comments

Three children commented about teasing and bullying, five statements described other difficulties they had, and three children used negative descriptors such as ugly, stupid and silly.

Bad behaviour

People make fun of you

Ugly people

Hard to understand other people

Touching other things like paper is horrid

You will get bullied a lot.

I'm silly

I'm stupid

Difficulty with noise

Difficulty with other people

Get teased

Find it hard when you meet other children, to mix with them

4.1.7 Responses from children in the 13 to 15 year-old group (n=10)

Nine children in this age group made twenty statements about AS. Six of the children wrote down three statements, as requested, and two children wrote just one statement. One of the young people in the group did not write anything in response to the question. Six statements were neutral, eleven were negative in content and three were positive. The neutral comments focused on facts about AS. Six young people made negative comments, one 13 year-old saying that he would not tell anyone. Teasing, difficulties in making friends and in understanding other people were mentioned by three young people. Their descriptions are given below.

13 to 15 year-olds

Positive comments

What profession you might have when you are older if you have it

What famous people might have it

You react to things very quickly

Neutral comments

How its pronounced

You say it how it is

I don't think like they do

They think in whole numbers while I think in decimals.

Want to be in their own world

Like my own space sometimes

Negative

I won't tell anyone.

You are arrogant

Get angry a lot

It is hard to make friends

Sometimes it is hard to know what people mean

I find it hard to understand other people

I find it hard to make friends

I find it hard to talk to people

I don't always understand what other people say

I don't like being teased

An unfortunate mental disorder which leaves the person feeling in some way isolated from the world

4.1.8 Responses from children in the 16 to 18 year-old group (n=15)

Thirteen of the fifteen children made thirty-seven statements about AS. Eleven of the children wrote down three statements, as asked, and others wrote either one or two. Five statements were neutral, twenty were negative in content and twelve were positive. Their descriptions are given below. It is encouraging that the older children made more positive comments than the younger children. This may reflect their growing understanding of AS and an awareness that there are some positive aspects or that adults have spent time discussing advantages with them.

16 to 18 year group

Positive comments

Good at some things like ICT and music

Observe small details that are obscure to others

A memory that amazes people

It is not a bad problem

There's no cure but it can be helped

It's just like tie-ing your shoes.

If you have it you may find other people look at things in a different way.

It doesn't make you different from everyone else. You're still you know matter what.

It's nothing to worry about

Its not a disease

Lots of people have it

Specific knowledge within a particular field of expertise

Neutral comments

Unusual obsessions

Makes me different

Yu take things literally

Its why you like _____ whilst others like _____

It's not the end of the world

Negative comments

Reading and writing and learning problem

Forgetful of things

Social difficulties

It is an unobtrusive mental problem

Difficult social skills

Learning difficulties

Lack of attention

Not being able to keep up good conversations

Difficult to understand things

Sometimes i talk too much

People who have it are socially inept

You'll get made fun of if anybody finds out

It can get awfully depressing

You're misunderstood a lot

No one bothers to try and help

The inability to understand oneself and others

Rejected by 'normal' society

It's why it is difficult to make friendships with others.

It's why you like ____ whilst others like ____

Social deficiency

Lack of conversation

4.1.9 Protection from bullying and teasing

This was most frequently mentioned by children and young people as a problem at school and outside, and also by parents. An extract from a talk by Danny Beath, a man with Asperger syndrome, who is now a professional photographer describes what he went through at school.

'Danny said he felt like an alien in the playground at school and thought at one time that he was adopted as he was so unlike his parents. He looked normal but he wasn't and staff assumed he could do everything, but he could not. He maintains that a child needs only to be 1% different at school to be bullied and that training is crucial to eliminate ignorance and educate people. His father was in the Armed Forces, working abroad and so Danny was sent to boarding school from the age of 8 years. He therefore had no respite from

being bullied 24 hours a day, seven days a week. Danny advises, ‘ Never send a child with ASD to boarding school..’ He refers to his teenage years as his Dark Ages as other children were very cruel and even now says, ‘ I still see them (teenagers) as dangerous – I still have this legacy.’ He much preferred University to school as Universities like diversity. He could go to what he felt comfortable with and there were lots of odd pebbles on the beach (at Cambridge).’

4.1.10 What is hard about having Asperger syndrome?

In addition to the question above, the children and young people were asked to write down ‘two hard things about having Asperger syndrome.’ In the 10-12 age group, their comments referred to making friends; understanding other people and work at school. For the 13 to 15 year group, there was reference to their emotions and feelings of anger or mood swings, and a comment from one boy about his progress being inhibited, in addition to friendships. For the older young people in the 16 to 18 year age group, there were more comments about their differences from others and the attitude of other people. Their anger is also apparent along with their use of expletives. The changes in the nature of their comments appear to mirror the changes in adolescence with increasing age. Their responses are grouped by age below. Where statements are grouped together, these are given by the same young person.

Responses from the 10 to 12 year olds

Getting friends

The teachers are cross

Other people

school

Not a lot of people understand you.

Don’t like writting – its too hard for me

Letting things go

Giving money away

Meeting new people and making friends

Responses from the 13 to 15 year olds

I don't know

Emotion

Bully problems

It stops me in life

It stops me from having an education

I am a loner

Mood swings

It's hard to make friends

It's hard to know what people mean

Frustration and anger

Calming down after shouting

Being teased

Not understanding

Reading people

People with it don't talk too much

Rather be alone

Responses from the 16 to 18 year-olds

Forgetting instructions

Spelling and writing and reading

Disorganised

Can't be sociable

Nerve

Fear of embarrassment

Getting down to study

The inability to socialise

Making friends

Understanding people

Writing

Having it is not hard because it is your life and you live with it because you don't know any different.

The fact that not much is known about it and when I was told it was just a title and a few small things that made me different but there was "no actual" things.

*There are people who don't give a flying **** about it.*

You get REALLY depressed.

The way 'Norms' (normal people) treat us.

Being excluded from society

I only tell those I trust

I found it hard to socialise with people without Aspergers

Uncontrollable depression and the inability to tell others of the cause of the aforementioned affliction

The level of ignorance towards the disability and its effects and the uniqueness between person to person

Having conversations with people

Staying in a crowded room

Talking to people

Having proper communications

4.1.11 Are there any advantages in having Asperger syndrome?

This question was not asked of every young person as the questionnaire was modified slightly and this question added after the first twenty children had completed this. Eight young people responded to this, seven of whom could think of an advantage. The ninth young person, a 16 year-old, replied, '*Nothing springs to mind.*' This ability to list advantages is encouraging and perhaps reflects the recent literature on AS where the focus is trying to shift from deficit to difference, and to suggest there are some advantages in the AS view of perceiving and acting on the world. Their comments are given below with their original spelling.

Advantages

11 year-old

Being able to solve puzzles eazyer.

Being able to consenstrate.

11 year-old

I like Mrs H being with me.

15 year-old boy

knowing you have it

confusing thoughts

15 year-old

very few advantages – people tend to take more care of you. We are smart and have a good memory and can understand some things more quickly than other people.

16 year-old boy

Having a good time with some good subjects (i.e. Biology, ICT, music)

16 year-old boy

I always tell the truth

17 year-old

I can understand and enjoy complicated things.

4.1.12 Satisfaction with their life at school/college and home

The young people were asked to rate aspects of their life at school or college, friendships and their future plans, in terms of whether they were very satisfied, quite satisfied, not very satisfied or very dissatisfied. Their responses are given in Table 14 below.

Table 14: Level of satisfaction with different aspects of their lives

Aspect of life	Very satisfied	Quite satisfied	Not very satisfied	Not at all satisfied	No response
School/college	9	10	8	5	2
Friendships at school/college	11	11	6	6	-
Homework	4	10	9	10	-
Test or exam results	8	12	3	9	2
Friendships outside school	9	14	6	5	-
Future plans	11	6	5	6	6
TOTALS	52	63	37	41	10
Combined	115		78		

Overall, there were more positive ratings than dissatisfied ratings, which is encouraging, although some aspects were rated ‘*not at all satisfied*’ by almost a third of young people (i.e. homework and test results). Some children and young people with AS have problems in setting down what they need to do for homework, and then are criticised by staff for the content or the amount or both. Some children and young people with AS set themselves high standards for their work and would be disappointed, even when they achieved a high grade. Each one of the ratings given

by the young people would need to be explored on an individual basis by staff and parents to identify the reasons which underlie them.

Some of the children and young people added comments to these. One 18 year-old (BS) commented on homework with which he was very satisfied stating, '*it was the best I could accieve with my intellect skills.*' And about exams which he also rated as very satisfied, '*It was a snap.*' Of friendship he commented, '*What friends there are, are OK.*' For his future plans, he wrote,

'I have no plans at this moment but I will make the best of my ability to help other people, to go further where my mind will take me.'

This was a very relaxed response which suggested he was currently feeling OK about his life and future.

4.1.13 How would they like their school/college to be different?

Twenty-three (68%) of the young people said they would have liked their school or college to be different, four said they were happy with the way it was and seven did not give a response to this question. One 16 year-old girl who did not want to disclose her diagnosis to the school said she did not need the school to be different and that,

'The school do not know, but I do not feel any different from any other pupil attending the school.'

Many had good suggestions for what they would like to be different and some of these could have been implemented. It again highlights the value of asking the children and young people themselves, rather than making an educated guess on their behalf about what might be of help. Three asked for action to be taken about bullying, and some commented on the lack of awareness of AS amongst the staff. Suggestions for what should be different (using their spelling) made by the children and young people were:

10 yr old

'for my work to be harder'

11 year-old

'A timetable would make life less confusing in primary school. I wish my school would keep the promise of an assistant. I have her for 3 hours a day and she goes to other children in different classes and doesn't help me. Talk to other boys/girls in my class and explain how I find it hard to understand what they say and how much they hurt my feelings when they say 'weirdo, sad.' School does not stop the bullying.'

11 year-old girl

I would like to have just the one teacher, no punishment and no homework.

12 year-old

Less homework

12 year old

I'd like them to put cameras up at school so that staff can see when children are being bullied.

13 year-old girl

Extra help with things I don't understand

13 year-old

better teachers.

13 year-old

Discipline with other pupils. Exams — most of the stuff we have never done and amount of work to be less, except for in RE because the class is so rowdy we hardly get anything done in RE.

13 year-old

It all.

13 year-old

less school hours, less homework and no PE

14 year-old

I would like them to listen to more than one side of a story before blaming anyone who witnessed an event.

15 year-old

Teachers need to know more about what it is like to have AS. My teachers have been told about it but I still feel they have a small knowledge.

16 year-old

no bullying

17 year-old

I would like to be helped with it.

17 year-old girl

*I would like them to give a **** to at least try to understand or help me.*

18 year-old

Shorter hours, no homework, better communication skills between people like me and teachers and more help in schools.

18 year-old

The whole system needs to be reorganised top provide more hands-on experience to its students and less paperwork, enabling people who need to be retrained within their jobs. Qualifications need to be based on adept ability and not written performance. That way the people who prove to be more able bodyed in their field advance faster and cost government less money so everyone's happy. People diagnosed with dislexia or who have dislexia type tendancys need to be given support but not in the essance of treating them in an infintile manor.

18 year-old

Staff who know exactly what they are dealing with.

18 year-old

Social groups with people who have appreciation of AS.'

4.1.14 Activities or sessions outside of school/college which provide help or support

The children and young people were asked: *'Do you see anyone else or do anything else that helps you, apart from things that happen at school/college?'* Very few of the children and young people mentioned other agencies outside school and college which provided support. A 13 year-old girl said that she went to youth club and piano lessons and that *'they all look after me'*; a 14 year-old boy said that he visited a psychologist, and another boy went to a local technical college with his mother for extra English, maths and ICT.

4.1.15 Descriptions of self and interests: 'All about me.'

The children and young people were asked to complete a number of statements to describe their interests, strengths, worst and best experiences at school or College, aspects of teachers' behaviour which might cause them difficulties, behaviours which might annoy other children and about their future plans. Adults with AS have written about the importance and value of meeting others with AS to appreciate that they are not alone in experiencing similar problems, and in sharing special interests and hobbies. The replies below illustrate the commonalities between those with AS, but also highlight differences, which caution professionals and parents from assuming all children and young people with AS have similar wishes, views and needs, by virtue of their diagnosis.

There were some fascinating and insightful replies, and some sad and moving statements about their experiences and wishes. These are given below in exactly their own words and spelling (corrected if the meaning is unclear). They have been presented separately for boys and girls, as there are suggestions that there may be differences between children and young people with AS depending on their gender.

There are not enough children and young people in the sample to explore this in any depth, but it is interesting to see whether they seem qualitatively different. Several children and young people mentioned computers and Playstations as special interests, and there was a preference for the sciences at school.

Responses from the 10 to 12 year-olds (n=10)

My special interests are....

Boys

Computers

Playstation 2

Playstation, computers, golf, piano and reading.

Rugby

Simpsons and Playstation

Space, science, star wars

Spiderman, swimming

Tractors

Girls

Buses and trains

Watching movies

My best subjects are....

Boys

Computer

Computers and history and art

Computers, choir

English, science

Geography, technology and science

Maths, science and English

PE

Science and art

Girls

Art

Science and PE

My worst experience in school/college has been when....

Boys

Being called names

French and HE

I bit a girl for bossing me

I was bullied

People hit me

When I was bullied.

When the teacher left the room and I got teased

Girls

I went over on my ankle.

My teacher sent me outside when I was very ill.

At school/college, I need help with....

Boys

Everything

Everything

French and maths

Maths

Maths

Nothing

Work

Girls

Maths

Maths

My best experience at school/college has been.....

Boys

Changing school

Going to the zoo

None

Playing

Rugby

When I got pneumonia and so missed the school trip

Girls

Playing chess

School play

My favourite TV programme(s) is.....

Often children and young people with AS enjoy programmes with very obvious humour that is portrayed visually by actions or cartoons, rather than by words and facial expression. Other favourite programmes are those which involve facts including quiz shows and documentaries. The lists for the children and young people in all age groups have these type of programmes in common.

Boys

Chuckle brothers

Futurama

Simpsons

Simpsons

Spiderman and Batman

The Simpsons and Quiz shows

Tom and Jerry

Girls

Documentaries

Eastenders

Some teachers make it difficult for me when.....**Boys**

Confusing because it is hard to understand them

Tell me what to do

They put me down (i.e. the maths teacher)

When they just ignore me.

Girls

No response given

Tell me to play the recorder

I sometimes annoy other children when I.....

Boys

Be noisy

I make noises and say I don't understand

Raise my voice when angry

Walk in late

When I used to lean on them

Girls

Chase them

They annoy me

When I leave this school, I plan to.....

Boys

Be a contractor

Be an actor

Get a job

Go to the Academy

Never go back

Race cars

Work

Girl

Go to St. X school

In the future, I would like to get a job as a.....

Boys

An actor

Computer designer

Computer game programmer

Electrician

Racer

Girl

I don't know

Responses from the 13 to 15 year-olds (n= 10)

My special interests are.....

Boys

Computers

Computers, weaponry, any mythology

Film making and computer games

Making things

Reading, playstation, learning

X box

Girls

Bratz dolls and Winnie the Pooh

Computers

Jig saws and bike riding

My best subjects are.....

Boys

Maths

Maths

Maths and technology

Maths, music, English, Science and French

PE

Physics

Sciences

Girls

French

Maths, history, ICT

RE and history

My worst experience in school/college has been when.....

Boys

At primary school when teachers took my clothes off in front of other children who laughed (I had sat in some porridge on the chair)

I accidentally caused a child to break his wrist at Rugby

I got picked on.

There is not enough space to describe every minute I spend there.

Unleashing temper

When I accidentally kissed my classroom assistant.

Girls

Being accused in the wrong

I was being scared with rubber gloves

Teased when I had braces.

At school/college, I need help with....

Boys

Fiddly things

Nothing

Organization

TO and HE

Understanding people

Writing and typing

Girls

Art and science

Maths, Science, English

Technology

My best experience at school/college has been.....

Boys

Getting an 'A' in my transfer test

Getting out of school

Learning

My buggy project in technology

Trip to Scotland

Girls

Doing well in French by coming second in my summer exam

Got an a in a science test

Taking part in games

My favourite TV programme(s) is.....

Boys

Cricket programmes

Don't watch

Family Guy, American Dad

Mythbusters

Pokemon, dillmon, simpsons, futurama

The Simpsons, Ed, Edd And Eddy, the Grim Adventures Of Billy And Mandy

Girls

Hannah Montana and Disney

That's so Raven; Sabrina the teenaged witch

The Simpsons

Some teachers make it difficult for me when.....

Boys

Ask me how I feel or about targets

Give me to much work.

Girls

Shout at me when I don't understand

Tell me to get my work done in time

When they talk too fast

I sometimes annoy other children when I.....

Boys

Hyper/encouraged

I am annoyed

I breathe, blink, be alive. Everything – all the time. Other children are horrible especially the girls. They are very sexist.

I don't know

In a temper

Miss obvious jokes or topics

Girls

Interrupt

Start shouting out loud

When I leave this school, I plan to.....

Boys

Be pilot

Get a job in helping animals

Go to university

Go to university and study game and film making

I don't have any ideas yet.

I don't know

To become a games designer

Girls

Get a job

Get a job

Go to university

In the future, I would like to get a job as a.....

Boys

Be a pilot

Director/actor

Executive of Rock Station games

I don't know

Scientist or doctor

Girls

A vet

Librarian

Pop star

Responses from the 16 to 18 year-olds (n=15)

My special interests are....

Boys

Animals and recycling

Animals and space

Computer games

Computer games

Computer hardware and gaming

Computer, reading, writing, TV

Computers and games

ICT

Movies, music and books

Music

Swimming, video games

Listening to music and playing various sports

Girls

Gothism and gaming

Swimming, bell ringing and animals

My best subjects are.....

Boys

All of them

Art

Biology

Biology and physics

English

English, history and RE

ICT

ICT

ICT and history

IT

Music and history

Science

Girls

Maths and geography

None

My worst experience in school/college has been when....**Boys**

Be bullied and name called

Being bullied

Bullying (enough said!)

Do you have a week?

Going into an exam without a scribe

I was put in Friday afternoon detention.

I was suspended for retaliation in an unjust situation,

Somebody has publicly abused my personal belongings

Studying for my college exams

Girls

I have been humiliated too many times to pick out one experience.

Throwing up in technology

At school/college, I need help with.....

Boys

Everything.

Getting the answer right and reading and writing

Irish, English

Maths

Maths

More than I could wright here.

Organising

Revision notes

Work and work again

Writing and reading and learning.

Girls

Everything

Spelling

My best experience at school/college has been.....

Boys

*Are you **** kidding me?*

Becoming a prefect

Getting a B in Maths

Getting a classroom assistant to help me

Getting my GCSE results

My performance in the school play

My school winning XX in 2006

Punching my year teacher at the formal (he deserved it).

When I finished.

When somebody got me annoyed and I fought back

With friends and when talking with Mr.

Girls

Going to London castle with the year group

Never had one, barring leaving

My favourite TV programme(s) is.....**Boys**

Lost

NCJS, Onepiece

Neon, Genesis, Family Guy, Gundama Wing, Cowboy Bebop

Scrubs, early Simpsons, Red Dwarf, Father Ted, Futurama, Family Guy

Scrubs, Smallville, Buffy, Angel

Shameless

Sitcoms

Sonic X

Star Trek, and discovery programs and educational programs and animal programs

The Simpsons

Girls

Don't watch much TV

Red Dwarf, Sex and the City, Desperate Housewives, CSI

Some teachers make it difficult for me when.....**Boys**

They put me down (i.e. the maths teacher)

When they started on me for not understanding work

Girls

They single me out and put me down

I sometimes annoy other children when I.....**Boys**

Anything I turn my hand to

Ask for repeats

I do my work and finish before them and my quirks

I don't annoy other children as I am friendly to all

I don't laugh at their stupid comments.

I perform random acts of randomness

I talk about movies too often

If I do, I don't know why.

Talk too much

They annoy me

When I do anything

Girls

I dress the way I do

I get things right

When I leave this school/college, I plan to....

Boys

Become an animator

Go to university

Go to university

Go to university

Go to university

Going to college of further education to do a BTec

I am in college and I will soon be quitting due to the behaviour of tutors.

I'll be honest. There is no point in planning anything. I have to take one day at a time and work through it.

I plan to study in Liverpool.

Revolutionise the transport and space industries

Work hard

Girl

Go to University to do Zoology and then specialise in entymology

In the future, I would like to get a job as a.....

Boys

Animator

Biochemist

Computer games and hardware, Alpha and Beta tester

Computer games programmer

Dump manager

Film-maker

Forensic scientist

Games developer or similar for computers

Not sure yet

Something to do with Science

Technical programmer

Girls

I won't be able to, let alone cope with one, sadly.

Someone who works with animals and insects

Some of the comments made above show the insight that the child or young person has into their experiences and other people's responses. They may have developed these without explanation from staff and parents or may be writing down what they have heard others say to them.

4.1.15 People who have helped the children and young people with AS

The children and young people were asked to rate the extent to which they had been helped by a number of people in their lives. Their responses are given in the Table 15 below. The key people they feel have helped the most are their family. Given the nature of the condition, parents are often unsure whether their son or daughter perceives them as helpful and whether the feelings and emotions involved are similar in kind and degree to those of their other children. These findings suggest that young people with AS are very well aware of the help and support they derive from their parents. This is another prompt for services to endeavour to support the parents and families as much as they can as they are the key resource in their children's lives.

What is also encouraging is the number of children and young people who state that they have been helped 'a lot' by their friends. Parents and professionals and individuals with AS themselves often speak of their problems in finding and maintaining friendships – and in fact sections in this report do identify many sadnesses surrounding these issues. Nevertheless, over half of the children in this sample refer to the support they have had from friends. Having even one friend at school is vital for these young people to act as interpreter, protector and companion

with whom to share their special interests. Teachers and support assistants are also rated well overall. As the children and young people have many teachers, it is hard to give a general rating to this question, and some children identified particular teachers who had given them a very hard time, which can then affect their trust and relationship with teachers generally. The mother of a 13 year-old boy said her son treated his assistant like his PA (personal assistant) and was very happy to have her support.

Table 15: Level of support that children and young people with AS felt they have had from different agencies

People who have helped	A lot	A little	Has not helped	Don't know	No response
My family	31	4	-	-	-
My teacher	14	16	5	-	-
My support assistant	15	11	3	4	2
My headteacher	9	7	14	5	-
My doctor	10	11	11	1	2
My friend	19	9	3	3	1
My psychologist	12	4	3	8	8
My speech therapist	7	6	3	8	10
Other person	5	5	2	13	9
Totals	122	73	44	42	32

4.1.16 People who should have helped, but have not done so

The children and young people were asked to state whether there was anyone who they felt should have helped them, but had not done so. Fourteen (41%) of the children and young people identified at least one person they felt could have

supported them but did not. These included teachers (3), parents (2), and a range of other professionals (7).

Specific comments made on those who should have helped included:

10 to 12 year-olds

My old school

My teacher from 2 years ago. She didn't try to understand who I am and always shouted at me. School is very hard every day. I hate it. I hope secondary school is better.

Friends

My school – they do help me but not a lot. (She does not have a support assistant).

13 to 15 year-olds

My doctor with my diet and allergies

My head of year should have come and talked to me if I had any problems

16 to 18 year-olds

Teachers

My teachers and my dad (who lived separately from the family)

My mum (who lived separately from the family)

The former SENCo of my grammar school

The government

One 16 year-old said that he would have liked more experiences with other AS teenagers since he was diagnosed 3 years ago. He had been on a six-week sailing course and wanted more similar experiences. A 17 year-old girl commented that there are '*hundreds of people who don't care.*' One 18 year-old listed a number of people he thought should have helped and who did not, which included social services, doctors, and other medical personnel.

4.1.17 Which of the following statements do you think the NICCY Review should say about services and support to children with AS in Northern Ireland?

Children and young people were asked to rate a number of statements provided on the support services in Northern Ireland in terms of whether these were very good, quite good, or not very good. They were able to tick 'don't know' to these. Their responses are given below by age group in Table 16.

Table 16: Ratings given by children and young people with Asperger syndrome to services in Northern Ireland

Statement	Very good	Quite good	Not very good	Don't know	No response
Services and help for children and young people with Asperger syndrome in Northern Ireland are	2	7	20	2	4
The support which schools give to children with Asperger syndrome is.....	4	5	17	4	5
Doctors, nurses and dentists in Northern Ireland are usually with children with Asperger syndrome.	4	12	8	7	4
Voluntary groups for children and young people with Asperger syndrome in Northern Ireland are.....	6	9	8	6	6
Most teachers are..... in understanding how to help children with Asperger syndrome.	4	5	20	2	4
Most professionals areat asking children and young people with Asperger	3	8	16	4	4

syndrome what they think about the help they need.					
Totals	23	46	89	25	27

Just over half (57%) of the ratings given were rated as ‘not very good’, but 23 (14%) of the ratings were very good and 46 (29%) were rated as quite good. So there is some degree of satisfaction amongst the 35 children and young people with what has been received. Some made additional comments, as follows.

An 11 year-old boy broke his hand and although his mother explained he had an ASD, he still had to wait 12 hours to see a doctor.

One of the children’s mother’s also wrote some comments in addition to her son about the long waiting times she had experienced in seeing professionals. She said she had waited about 18 months to see a paediatrician; two years to see an OT; 18 months to see a speech therapist and then 12 months for the second appointment to begin the therapy; 18 months to see a dietician; 5 years to complete the Statement as the school was reluctant to complete the reports; and three years to see an Educational Psychologist. It is difficult to comment on this without knowing the views of the professionals concerned. However, it is clear from this Review that not only parents were concerned about waiting times, but the professionals, too, felt these were unacceptable. It will be the case for some children and young people and their families that their needs are not as great as others, but clear messages need to be given to parents about the reasons for the delays and an idea given as to when they might be seen. The NIASA plan (NIASA, 2003) which reported on the situation in England also reports long delays for diagnostic assessment, and states clear time intervals which should be aimed for between referral, diagnosis and the start of interventions.

An 18 year-old person also commented on the nature of help or lack of it, both positive and negative. For the first statement, he said that services were ‘rubbish’. Help in schools he had attended ranged from very good to not very good. He felt that

doctors and health personnel were generally 'very polite' . He had had good support from Autism Initiatives, but generally felt he had 'nothing over an 11 year period' in his younger days. He was very derogatory about professionals generally stating that, 'They have a nose in the air and they don't talk to us.' He added, 'They need to talk to us as we are here to stay and are not leaving.' Another 18 year-old wrote, services are 'nearly non-existent, barring charities that can barely sustain themselves'.

4.1.18 Other comments made by the children and young people

At the end of the questionnaire, the child or young person was invited to comment on anything else not previously mentioned. Twelve children and young people chose to make additional comments. This clearly demonstrates that children and young people value being given the opportunity to comment on services, and that we can learn much from what they suggest. They made the following remarks:

I was uncomfortable with answering the questions. I would like to meet people like me.

I hate quizzes like this as I find them intrusive and hard to fill in.

I asked the mother of the first boy to elaborate on this and she said it was not the nature of questionnaires he disliked but his concern about writing the correct answers. Other children and young people with AS have concerns about committing their feelings and ideas to print as it is a permanent record and so cannot be changed and some want to do the task perfectly and worry that it might be below what is expected.

A 16 year-old boy said:

'I am scared in case I don't get to University as people might be good at one thing and bad at another (e.g. ICT).'

A 17 year-old said:

'There is absolutely nothing in Northern Ireland for aspies. The people in schools give no support and if you tell anybody you have Asperger's, they either laugh and make fun of you or try to exploit it.'

This highlights the issues of disclosure mentioned earlier and points out the need to do this carefully and in a planned way.

A 12 year-old boy said: *'I don't really mind having AS'*, although he had complained about being teased and name-calling. He did have some friends and some teachers who understood and his parents talked to him about his problems.

A 15 year-old boy said he would have liked more help in making friends, and another 16 year-old boy wrote:

'Ignorance of Asperger's often causes discrimination. My experience of it has set me on a trail of suicidal depression.'

A 17 year old suggested:

'There should be talks in schools about Asperger syndrome so that people understand better.'

An 18 year-old said: *'The aspect of having AS is much like a double edged sword with the exception of having no choice as to whether you have it or not'*. He made the suggestion that perhaps in the future it will be possible to integrate computer components into the brains of people with AS (as in the film *Johnny Mnemonic*) to allow them to function better in the neurotypical world.

The final comment was from a 17 year-old girl said:

'I wish for people to merely make it easier for us aspies. Our lives are horribly hard. We are forced to live in a norm world. Why can't someone try living in ours?'

This suggestion sums up the position of most children and young people with Asperger syndrome, and the suggestion made is extremely useful. Much of the literature written by those with AS suggests that professionals need to try to get into the head and the shoes of children and young people with Asperger syndrome to see the world from their perspective. Many adults with AS writing about their condition use terms such as *alien, other world, wrong planet, inability to understand Earth*

rules, to describe their situation. Events such as the Autscope conference which have been set up and designed for people with AS allow people with AS to experience a '*world which is based on Aspie rules.*' One of the strategies they have devised which facilitates interaction or prevents 'unwanted' interactions is a badge system. During the conference delegates can wear a green badge if they are happy to interact with anyone; a yellow badge if they would like to interact but only with certain people (the names of whom are written on the badge) and a red badge which shows that they do not want to interact with anyone at the moment. Some children and young people and adults with AS can give the impression that they do not wish to interact with others by their non-verbal behaviour and so wearing a green badge can invite others to speak with them.

SECTION 5: FINDINGS

Data from the Parents and Carers Of Children and Young People With Asperger Syndrome

5.1 Introduction

A questionnaire was designed for parents of children with AS (see **Appendix 4**). These questionnaires were sent out by Autism NI, Asperger's Network and by professionals in Northern Ireland. Some parents also responded to newspaper articles and the website which publicised the Review. A total of fifty-nine parents returned a questionnaire to give data about their son or daughter. Three parents had two children diagnosed with an ASD, one having Asperger syndrome and the other child having a different ASD. They completed the questionnaire in relation to their child with AS.

The child population of Northern Ireland aged from 10 to 18 years at the time of the Review was approximately 152,000. The expected numbers of children aged 10 to 18 with AS, based on the prevalence rate of 36/10,000 was 547 and the actual number recorded by the Department of Education in post-primary schools was 358. This parent sample therefore represents 16%, or about one in six, of the population of parents with a child with AS aged 10 to 18 years living in Northern Ireland.

It may be that those parents who were not satisfied with the services and support were more likely to complete the questionnaire to register their dissatisfaction and so it is possible that the sample is skewed towards those who felt services were not good.

This sample does not represent the total population of those parents who have a child with AS for a number of reasons:

- It was self-selecting and not a random, compulsory sample selected on certain criteria;

- It only reached those with a diagnosis who were in receipt of a service or who might access the Internet or find out about the review via the newspapers, a voluntary group or a professional;
- It does not include those whose children are not yet diagnosed with AS;
- It does not include those who are not able to read/and or write at the level required by the questionnaire.

The views of this sample of parents will help professionals and voluntary groups to evaluate their practice in the light of the comments made. Some of the comments are very positive in relation to some aspects of the service and others point to areas in which they would have liked support or to ways in which they would have preferred to be supported.

Fifty-two (88%) of the questionnaires were completed by the child's mother, six by the child's father or step-father (1) and one by the child's foster parent.

5.2 Gender of the children and young people

There were forty-seven boys and twelve girls in the sample, giving a ratio of 4:1.

5.3 Ages of the children and young people in the sample

The ages of the children and young people are given in Table 17. There were nineteen children in the 10 to 12 year group; nineteen children in the 13 to 15 year group and sixteen children in the 16 to 18 year-old group giving a good distribution across the ages. There were five questionnaires returned from parents whose children were under the age of 10 years, and these have been included in the analysis too.

Table 17: The age in years of the children/young people whose parents/carers completed a questionnaire

Age in years	Number of children/young people
Under 10	5
10	7
11	8
12	4
13	12
14	5
15	2
16	10
17	3
18	3
Total	59

5.4 Area in which they lived

Parents who completed the forms came from all five ELBs in Northern Ireland (see Table 18). It would have been better to have had more from the Western area and for the totals to reflect the total population of each region, but time constraints did not allow for more parents to be recruited.

Table 18: Area within which the parents lived in Northern Ireland

Region	Number of AS in post-primary	Number of families	Percentage of total families in the Review
Belfast	63	11	19
North Eastern	40	17	29
South Eastern	111	10	17
Western	56	2	3
Southern	88	19	32
Total	358	59	100

5.5 Length of time in which the parents had lived in the area

The vast majority of parents had lived in the same area for the whole of the child's life, and so were reporting on services in just one area of Northern Ireland, with only five families living in the area for less than 5 years (see Table 19). One of these parents had two children, one of whom had been diagnosed 12 months before they came to Northern Ireland when they were living in England. Another parent of a 10 year-old child had also lived in England and lived in Northern Ireland for just 3 years, but received the diagnosis in Northern Ireland.

Table 19: Length of time the parents had lived in the area

Length of time in years	Number of parents	Percentage
Over 20 years	31	53
11 to 20 years	20	34
5 years or less	5	8
6 to 10 years	3	5
Total	59	100

5.6 Current diagnoses of the child/young person (n=59)

The vast majority had been diagnosed with AS (78%), with only six children being termed high functioning autism (HFA) instead. Five parents were given both diagnoses of Asperger syndrome and HFA (see Table 20).

Table 20: Current diagnoses of the child/young person (n=59)*

Diagnosis	Number of children	Percentage
Asperger syndrome	46	78
High functioning autism	6	10
AS and HFA	5	8
Other	1	2
Not given	1	2

*Some children were given more than one diagnosis.

Over half (56%) of the children and young people had additional diagnoses, too, twenty-four having one additional condition (see Table 21). Some of these conditions

are known to have an association with autism, such as epilepsy, but others do not (e.g. diabetes, heart condition).

Table 21: Additional diagnoses in order of frequency

Additional diagnoses	Possible	Definite	Number of children	Percentage of total sample
ADHD/ADD	1	17	18	31
Dyslexia	3	2	5	8
Dyspraxia	1	5	6	8
Tourette's	1	1	2	3
Moderate LD*	-	1	1	-
OCD	-	1	1	-
Anxiety disorder	-	1	1	-
Hydrocephalous	-	1	1	-
Diabetic	-	1	1	-
Heart murmur/disorder	-	2	2	3
Weak muscle tone	1	-	1	-
Epilepsy	-	2	3	3
Cook's syndrome	-	1	1	-
Noonan's syndrome	-	1	1	-

5.7 Age at diagnosis

The age at which the children and young people were diagnosed is given in Table 22. Sixty per cent of the children were not diagnosed until late primary age (i.e. between 9 and 11 years) or post-primary age. Five (8%) of the children were diagnosed in the early years, before the age of 5 years, seventeen (29%) were diagnosed in the early primary school years (aged from 6 to 8 years); and twenty-one children (36%) were diagnosed in the last years of their primary school (aged from 9 to 11 years). Fourteen children (24%) were not diagnosed until they were of secondary school age.

Table 22: Age at diagnosis of the children and young people in the sample

Age at diagnosis	Number of children	Percentage of children
2	2	3
3	1	-
4	2	3
5	-	-
6	2	3
7	6	10
8	9	15
9	5	8
10	6	10
11	10	17
12	7	12
13	2	3
14	1	-
15	3	5
16	1	-
Don't know	1	-
Not given	1	-
Totals	59	100

It is likely that the younger children in the sample were diagnosed at a younger age than the older children, as professionals have become more experienced and methods for identification have improved.

5.8 Satisfaction with diagnosis, as rated by parents

In analysing these data, it is important to consider how many years ago the child was diagnosed. The expectation and hope within services is that age at diagnosis is decreasing, that there will be fewer parents waiting a long time and that the assessment process itself is getting better. As this is a sample of children and young people aged 10 to 18 years, and diagnosis of AS is possible by the age of 5 years, then some of the sample might have been diagnosed thirteen years ago and their parents may be commenting on practice some years ago. In reporting these data

then, the age of the young person now and his/her age at diagnosis is given together. Forty per cent of the parents were satisfied overall with the diagnostic process (see Table 23). At least six parents had paid for a private diagnostic assessment as they had been frustrated by the waiting times or had not been in agreement with the opinion of local professionals. Almost 60% of parents were not satisfied, seventeen parents stating that they were not at all satisfied.

The parent of a 10 year-old boy said she was referred initially by the health visitor to a behaviour management specialist which was not helpful, and the mother felt they had wasted a number of years. The specialist said we were doing *‘all the right things,’* but nothing improved. *‘A GP we talked to was very dismissive of my concerns and discharged my son.’*

Table 23: Level of satisfaction with the diagnosis by the parents

Level of satisfaction	Number of parents	Percentage
Very satisfied	9	15
Quite satisfied	15	25
Not very satisfied	17	29
Not at all satisfied	17	29
Not given	1	2
Total	59	100

5.8.1 Those parents/carers who were very satisfied

A parent of a 10 year-old child who was diagnosed at the age of 6 years (i.e. four years ago) and was very satisfied, said:

‘I am a very pushy parent and I know my rights and have an excellent network of contacts and friends in relevant professions who helped me get a diagnosis quickly. I know I was very lucky in this regard.’

It is highly likely that those parents and professionals who have the knowledge and resources to press for support will get a better deal than those who do not. It raises a number of ethical issues in terms of fairness, and reminds services to have systems

in place which allow those children and families who are less able, for whatever reason, to access and receive good services.

Another very satisfied parent of an 11 year-old child, who was diagnosed at the age of 10 years (i.e. just a year ago), said that,

'the diagnostic process was quick, but we were left on our own afterwards and there was no follow-up service available. We were given leaflets and advised to contact a voluntary group for support.'

Again, many professionals involved in diagnosis know that support and follow-up sessions are important and good practice, but they are often not able to deliver this due to the lack of resources.

5.8.2 Those parents/carers who were quite satisfied

A parent of a 13 year-old who was diagnosed just a year ago, at the age of 12 said,

'We had to take our child to be privately assessed as health education were not forthcoming with correct services. It was only after private diagnosis that statutory services took notice of our concerns. We had 7 years of hell.'

Another parent went for assessment privately and said neither the primary nor secondary school picked it up.

Another parent of a 14 year-old diagnosed four years ago said,

'The diagnostic process was fine. It was the years leading up to it that were not fine.'

A parent of a 16 year-old who was diagnosed at 13 said they were quite satisfied as they went privately, but were unhappy that neither the primary or secondary school staff had picked it up.

One 16 year-old girl who was self-harming was seen several times by a psychiatrist before AS was diagnosed.

A parent of an 18 year-old diagnosed nine years ago said,

'I never received a comprehensive (or any) written report. I was disappointed considering the fact that there were several professionals involved. It would have been useful to read over a diagnostic evaluation after receiving a verbal diagnosis.'

Practice in the UK in terms of providing good written reports for parents has improved considerably in recent years, in some part due to the Statementing process, where all professionals involved are asked to submit a report which is seen by parents. Practice still varies, though, in terms of how good these are and how well the child is described. Ideally, a report should be given which supports and explains the diagnosis and makes recommendations as to how the child might be helped. Some diagnosticians might also write a separate report or letter to the child themselves. For example, Professor Elizabeth Newson, who worked for many years at a diagnostic clinic in Nottinghamshire, wrote a letter to some of the children she saw for assessment explaining what Asperger syndrome was and elaborated on any concerns or questions the child might have had (Newson, 2002). It is good practice for professionals to read through their reports to check on whether these give a detailed and positive account of what was done, found and recommended, with any jargon or abbreviations or tests clearly explained.

5.8.3 Those parents/carers who were not very satisfied

A comment from the parent of a six year-old child, whose child was diagnosed early, at the age of three years, is included because this assessment was done relatively recently, and clearly shows the emotional demands of such sessions.

'It was a very intensive afternoon. One was questioning us on his history, while we were more interested in how he was responding to questions on the other side of the special glass. We felt in shock almost and numb the next day. Now

we had a diagnosis but we were left for months on our own wondering how to move on. There should be more than one session at this critical point.'

A parent of a nine year-old who was not diagnosed until he was 8, said she knew he had an ASD four to five years before the diagnosis and so was concerned that his diagnosis was very delayed. Another parent of a 13 year-old boy who was diagnosed at 11 felt similarly unhappy because her son had been diagnosed as having ADHD and the AS was missed initially. Prior to the diagnosis of AS, professionals thought he had a specific language disorder. It is difficult to differentiate between conditions as there is overlap between AS, autism, speech and language disorders, dyslexia, ADHD and attachment disorder. Some children may have one or more of these conditions. Those who have been working in the field for many years are still debating the boundaries, and the similarities and differences between different conditions (e.g. Bishop, 1989; Kugler, 1998). Giving parents clear information on what they feel might be the problem and the basis for this, with regular reviews and discussions of this, might allay the concerns of parents who do not feel sure that the professionals have 'got it right'.

Again, a parent of a nine year-old child who was only diagnosed a year ago complained of the lack of information given at diagnosis and following. She said,

'I was just told what my child had and nothing more. I have had no help from anyone. I had to pay to get a speech therapist myself.'

And another parent of a 10 year-old child diagnosed six years ago said she was given no support or information following diagnosis.

In the West Midlands region of England, a Parent's Pack has been produced which ALL parents receive now at diagnosis. This was created as many parents in the region used to be given either limited information, outdated information or badly copied leaflets on ASD. The Parent Pack is professionally produced and contains some leaflets as standard, on issues that parents are likely to want information on (e.g. what is AS; interventions; educational systems; support services and voluntary organisations), and accompanied by leaflets for local services.

Another parent of a 10 year-old, diagnosed at 8, was satisfied with the diagnostic process, but not with the 18 months wait, and another parent of an 11 year-old child who was diagnosed three years ago said she had to wait three years for a diagnostic assessment.

A parent of an 11 year-old boy diagnosed at the age of 7 commented on systems being very cumbersome and on the lack of coordination between services, saying that she had had six different appointments with different personnel. Again many areas have now tried to group professionals together within a team so that the family and the child see several professionals in one place and on the same day.

A parent of a 13 year-old (diagnosed at 8) said,

'I couldn't get anyone to take me seriously about suspecting autism until she started self-harming. A psychiatrist diagnosed her very quickly eventually but it was a very frustrating process.'

5.8.4 Those parents/carers who were not at all satisfied

A mother of an eight year-old boy diagnosed just a year ago said it had taken her five years in total to get a full diagnosis. He had been discharged from the clinic at the age of 2. The only information she was given at diagnosis was a PAPA leaflet.

The mother of an eleven year-old boy said she had thought her son had a problem from the age of three, but the child psychologist told her GP she was imagining this. He was not then diagnosed until he was seven, four years later. A similar comment was made by the mother of a 17 year-old who was not diagnosed until he was eleven. She said,

'I knew there was something wrong since the age of two but my own doctor and health visitor would not listen. The school didn't listen. It was only by accident that I met Dr XX who helped him.'

This again raises the question of initial and post-qualifying training in the alerting signals for ASD for primary health care professionals. Professor Ann Le Couteur and a group of professionals and parents made a video entitled *Autism Awareness* specifically for health professionals in recognition that most get very little information on ASD during their training. More recently, Professor David Skuse and Rebecca Chilvers in London have produced a DVD entitled the '*Hidden face of autism*,' to increase awareness and to give information about a new diagnostic tool known as the 3di (see www.ixdx.org).

A number of parents have more than one child with ASD and this can also cause diagnostic difficulties and delays. It may not be clear whether another sibling has the condition or whether it is learned behaviour. This delayed the diagnosis of a 12 year-old boy who was not diagnosed until the age of 11. He has an older brother with AS, but his parents had to press very hard for the ELB to undertake a statutory assessment.

The parents of another 12 year-old boy who was diagnosed two years ago said they felt blamed for their son's difficulties. When they described their son's problems, they were referred to a course on parenting which they found very distressing and frustrating.

'Meanwhile, he was developing more bizarre behaviours which we had no strategies to deal with. He was eventually diagnosed by a private psychologist.'

The parents of a 13 year-old boy obtained a private diagnosis when he was 10, but then found they had to get a diagnosis from other statutory professionals before Education and Health would accept this. This is an issue when parents seek and obtain a diagnosis from an independent or private professional. As the diagnosis might suggest extra or different resources from Education and/or Health, then many ELBs and HSSBs would wish to come to their own judgement on this. Where private professionals make recommendations, those working in the ELB and HSSB may not agree, or may need to do their own assessment. This may be particularly true if the private assessment was done many miles outside the child's home area. To parents this can be very upsetting and cause further delays. It is for this reason that the

NIASA report (NIASA, 2003) advises that diagnostic assessment *should be* carried out locally by professionals employed within Health, Education and Social Services. In England, as mentioned previously, fewer referrals to private or independent clinics such as Elliott House, are being made for diagnostic purposes. However, parents may still seek private assessment for interventions, or may pay privately for particular interventions and therapies.

The mother of a 14 year-old boy who was diagnosed at 11, said that,

'From the ages of 3 to 11 I feel Dr. XX avoided diagnosing despite my son having all the symptoms. I had to push to get anywhere. I was most annoyed that the speech and language therapist in school admitted that she thought he had AS, but didn't have the opportunity to relay that to anyone in health. She said, 'I'm educational, not health.' I was furious that someone could see my child had a condition and didn't see fit to share her thoughts with another professional. It would have made life so much easier if she had done so.'

This comment highlights a number of issues. The first is the boundaries that exist between those working in Education, Health and Social Services, and attempts are being made to make these more permeable with greater communication and sharing of information. The second issue is that in some areas, there are strict rules as to who is 'allowed' to make the diagnosis of AS or ASD. Often speech and language therapists recognise AS, but may not have received specific training in diagnosis and are directed to refer the child on to those that do without sharing their views with the parents. Again, the NIASA report (NIASA, 2003) tries to streamline and explain the process for parents and professionals from first concerns to diagnosis.

A father of a 17 year-old boy who was diagnosed at the age of nine, said the whole diagnostic process was slow and impersonal, and at the end, they were given a video to watch and told that children with AS can become suicidal in adolescence, which he found very harrowing and worrying.

Finally, the parent of an 18 year-old boy who was diagnosed when he was 11, said,

'It took an 'appalling length of time to diagnose this. You are fobbed off as being too caring or over the top, particularly when you are a lone parent. You are treated as the lowest form of life and intelligence.'

5.9 Current school/college placement

As expected, the majority of children and young people attended ordinary mainstream schools and colleges (see Table 24). Four children attended a special school and one attended a special unit for children with communication disorders.

Table 24: Type of school/college placement attended

Type of placement	Number of children
Ordinary mainstream in our home area	39
Ordinary mainstream outside our home area	8
Special unit or class in a mainstream school	3
Special school for children with moderate learning difficulties	3
School for children with social, emotional and behavioural difficulties	-
Special school for children with severe learning difficulties	-
Special school for delicate children	1
Special school for children with autism and Asperger syndrome	-
Communication or Language Unit	1*
Home educated	-
No education at present	1
Training centre	1
Other, please specify	2

TOTAL	59
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5.10 Distance of school/college from the parents' home

Over half the children lived within 3 miles of the school or college (see Table 25). Others lived further away, and in some cases, they had been attending the local school, but their parents had chosen to move them as they were very unhappy with the school. None of the parents commented on problems relating to travel to school or college.

Table 25: Distance from school to home

DISTANCE FROM HOME	Number of children	Percentage of children
Walking distance	15	25
1 to 3 miles	17	29
5-10 miles	21	36
11 to 20 miles	4	7
20-40 miles	1	1
over 40 miles from home	-	-
Not applicable	1	1
TOTAL	59	100

5.11 Satisfaction with current school/college

Almost three-quarters of the parents were satisfied with the child's current school or college placements and said this was their greatest source of support (see Table 26). Some of these parents, though, had experienced great problems with schools in the past and had taken their child out of the school. A quarter of the parents were not satisfied with how the school or college addressed their child's needs. Some of their comments are given below.

Table 26: Satisfaction with school/college as rated by the parents

Satisfaction	Number of children	Percentage of children
Very satisfied	23	39
Quite satisfied	19	32
Not very satisfied	13	22
Not at all satisfied	2	3
Not applicable	1	2
Not given	1	2
Total	59	100

It is very heartening and encouraging to read the positive comments from parents where schools and staff are working very well with them to meet the needs of their son or daughter. Conversely, where parents do not feel supported by schools who misunderstand the child or young person and/or refuse to change to accommodate their particular needs, then parents who are already very stressed have an even greater difficulty. When services and people who are there to help actually make the situation worse, this can be very dispiriting and depressing for parents. As one parent said, *'I worry what awaits him each day as he goes off to school.'* So dealing with negative events that actually happen, and the worry about what might happen, create a permanent pressure on parents who need to feel some support and respite when their son or daughter are away from home and not the opposite. As said earlier, all five ELBs have set up autism Advisory Teams and there is evidence that their work is having an impact on both the understanding of staff and the support they are giving. But there are many children and young people with AS, and some schools and colleges are slow to change their routines and procedures to accommodate students who are different, so it is likely over the next few years that some young people will receive less than adequate support – often because the staff do not know how best to help and, hopefully, rarely because they do not want to help. There are a number of CDs and DVDs available now which can enhance and add to the work of the outreach teams and Autism NI and Asperger's Network. These are referenced in the *Further Reading* lists at the end.

One father said the Headteacher did not understand his son's problems: he excluded his son from school for throwing a chair, during an incident in which his son

misunderstood what was being asked and therefore became angry. This parent found it hard to explain his son's perspective to the Headteacher who became increasingly annoyed over time. When the father said,

'My son has a right to be educated, '

the Headteacher replied,

'Yes – but it doesn't have to be in my school.'

A mother of a 10 year-old child also had experience of a Headteacher who did not understand her child, but happily she has a very good relationship now with the new Principal. The former Headteacher viewed her child as a naughty boy and told her that her son wanted to be the *'class clown.'* His mother's view was, in fact, the opposite of this, that her son wanted to hide away from the other children, and that his behaviour in class, particularly in Circle Time was anxiety-related. Her son was very negative at this time and said to his mother,

'I wish I could die and then I wouldn't have to face it.'

The new Principal, in contrast, recognised her son would have difficulty in taking part in a school concert on the stage and so found a role for him, saying,

'I need someone to stand at the door to give out the programmes.'

This gave him a sense of responsibility and achievement.

Her son is much better understood now, but still finds school a great strain and is *'like an animal let out of a cage when he gets home'*. This is quite common for children with AS and ASD. The child can be very different at home and school, and parents and staff can find it hard to 'believe' the different accounts of the child in both settings. Some advisory staff now work in both settings and can see this for themselves and offer advice and guidance to both parents and staff on what they might do to prevent or minimise these emotional outbursts. For example, staff can

debrief the child at the end of the school day and remind them of the positive things they have done and achieved before going home. Parents can provide a structured 'coming home' routine and provide activities which the child looks forward to and enjoys immediately on his/her return home. One parent said that her son goes into his bedroom for about an hour when he gets home from school, sometimes getting under the bed with his favourite objects and activities. He is 'getting away from it all' and calming himself down. She does not insist he joins the family until he is ready to do so. From the comments from the children and young people themselves, it is likely that Gameboys, Playstations, time on the computer or watching videos serve the same function and should be allowed. Most adults with AS say that they need time to be alone. There are some issues here, though, in that some children and young people can spend many hours on these during the day and into the night – and a system of rationing is often required (as with other adolescents without AS). This is often easier said than done.

A survey in Manchester by Brenda Nally (unpublished conference paper) on video watching found that parents were often reluctant to admit how many hours their children with ASD spent watching videos, and how many replacement machines they had had to buy, for fear of criticism by professionals. The reality is that most children and young people with AS spend many more hours indoors at home than other children and young people of the same age as a result of the need for supervision, limited friendships, and often their lack of skills at sport or other adolescent leisure pursuits such as skateboarding, football, cycling and generally 'hanging around' with their peers. It is likely that the more Services can offer to parents by way of resources to help fund activities, holidays and befrienders, the less time their child would spend on the same activities. Some parents spoke of the fun their children had had when outdoor activities had been funded and organised and how they would like much more of this. As adults too, these children and young people will probably spend more time on their own than the general population, and the more others can do to increase their repertoire of skills and interests, the richer their lives will be.

5.11.1 Comments from parents/carers on their satisfaction with schools and colleges

Some of the comments made by parents on school and college placement are given below in order from 'very satisfied' to 'not at all satisfied'.

5.11.1.1 Parents/carers who were very satisfied with primary school

Eight year child diagnosed a year ago

'The school has been excellent and even provided training for staff.'

Ten year-old child diagnosed this year

'He is accepted and given support to do his best and to develop interests. His classroom assistant has received recent additional training in the management of behavioural problems.'

Ten year-old child diagnosed at the age of 6 years

'The school could not be better. The Principal diagnosed his condition a year before the medical professionals. All the teachers are supportive and well trained.'

Eleven year-old child diagnosed at the age of 8

'At his first school, he was treated like an outcast. He became very depressed. He was being bullied very badly and the school refused to do anything about it so we took him out of it. We are very satisfied with the school support but not with the Education Board.'

5.11.1.2 Parents/carers who were 'very satisfied' with special school

Ten year-old child diagnosed at the age of 8

'The staff are well trained and understand his behaviour.'

Eleven year-old child

'Her teacher is excellent.'

Some parents had worked in their child's school as an assistant and so had seen and heard some of the incidents that occurred. One parent said she saw *'some awful things.'* The teacher would ask children to get into pairs and her son was never picked. She said the teacher made this worse by saying publicly to one of the girls,

'Will you work with X as no one else has chosen him?'

5.11.1.3 Parents/carers who were very satisfied with secondary school

Eleven year-old child diagnosed at the age of 4

'The grammar school is very open to ideas on how to help him.'

13 year-old child diagnosed at the age of 8

'They are trying very hard to work in partnership with us for the best.'

14 year-old child diagnosed at the age of 9

'The school has shown us every support possible and has constantly listened and acted in his best interests and they are very well supported by the outreach teacher.'

14 year-old child diagnosed at the age of 10

'He has excellent classroom assistants who liaise regularly with us.'

15 year-old child diagnosed at the age of 12

'They have tried hard to meet her needs and we can phone any day if we need to talk.'

15 year-old child diagnosed at the age of 2

'I am extremely happy with the support which he gets from his outreach teacher. She is excellent and a great help.'

16 year-old child diagnosed a year ago

'The pastoral care teacher is extremely supportive. All her teachers have been informed.'

17 year-old child diagnosed at the age of 9

'The school is excellent and the education board very helpful.'

5.11.1.4 Parents/carers who were 'quite satisfied' with school/college

Primary school

Some parents were fairly satisfied with the support from school or college, but some of these had some issues.

Six year-old child diagnosed at the age of 3

'He has many outbursts over trivial issues. I wish the ASD outreach adviser could withdraw him to discuss social issues and liaise with us as parents. Nice as she is, she is spread too thinly. The support is not regular enough to be effective.'

Nine year-old child diagnosed at the age of 7

'Excellent, as his teachers want to help and understand him completely, but we had to move him out of his first school. The nursery school was excellent as teachers took time to help him with certain difficulties, but the P3/4 teacher did not want to understand his problems and actually added to them.'

11 year-old child diagnosed at the age of 7

'I have to bring him home at 2pm instead of 3pm like the other children as they can't cope with him without the assistant. I would like more support. I feel I am imposing on teachers and pupils by having him with them. It's very kind of them to put up with us.'

Shortening a child's day or asking parents to take their child home for lunch is not uncommon in schools in the UK, but there are important issues here. It clearly adds to the parents' stress and disrupts their day. In addition, it does not give a good message to other children and staff about children who are different, in that it perpetuates the idea that some children should be excluded from some parts of life which their same-age peers are not. This comment also shows that this mother feels

guilty for adding to the work of the school. Having a child with AS is not something parents opt for by choice, and we have to ensure that they feel welcomed by services and professionals, not merely tolerated. Having open discussions with parents and the child about what they feel they need, and putting in the supports that are required, will help the former to feel valued and listened to.

5.12 Transition to post-primary school

Case study: Eleven year-old child

At transition to secondary school, one parent said she had an horrendous time. This is her story:

'All the planning was done but then the new Headteacher said he did not want him at the school, even though the ELB had named the school on his Statement. So all the work had to be put on hold. At the start of the new term, there was still no place for him. A solicitor took up the case and the school was told to take him. We were then phoned on Monday to say he could start on Tuesday. We had to rush to get his uniform and he had missed the first 10 days of his new school!! He then had a series of temporary CAs for the first 2 months. Not surprisingly his behaviour was atrocious, to the extent that the SENCo said he was psychotic. Fortunately, his current LSA is excellent. But, he hates school and is physically sick at least once a week at school. He is anxious and bullied. He has one or two friends by virtue of his Playstation machine, which staff have said he should not bring to school - but he said he would have no friends if he did not have this.'

Often the issue with transition is that the child and the parent do not know until very late where s/he is going to move on to – when a change of school is required. There is then insufficient time to prepare the child or young person. One of the parents in the sample was told that her son would be prepared for the move to secondary school by staff of the new school, but in the event, she received a phone call to ask if she could take her son on the visit. This mother was upset by this as it seemed a lack of care, and her son was not keen to visit the school with his mother as escort.

5.13 Special school

14 year-old child diagnosed at the age of 11

'The school is good educationally but not as good at addressing his social needs.'

5.14 Secondary schools

16 year-old child diagnosed at the age of 12

'Some teachers are very good and very accepting. Some are very surprised at their own misjudgements, and some are indifferent. She likes her school and her teachers.'

This sums up well the fairly typical scenario in secondary schools in terms of staff response. There are some who are able and willing to adjust and differentiate what they do, those that do not immediately see the need to do so until incidents occur which make the child's understandings and needs very clear, and then those staff who are told and know the young person needs something different but are reluctant to change their practice. As the awareness of AS continues to increase in schools, the numbers of staff in each group should change in favour of the first group.

16 year-old child diagnosed at the age of 15

'Our daughter does not want the school to know, but although the school is not aware of her AS, they do acknowledge her differences but accept her as she is and say she is a welcome breath of fresh air.'

This comment raises an issue experienced by some parents of children with AS who do not want their parents to disclose their diagnosis. In this instance, it appears that no problems arose from not sharing this with the school. Each family and child/young person has to weigh up the pros and cons of disclosure and their decision will be affected by the severity of the difficulties, the view of the young person, the nature of the school and the response of staff. It is not possible to prescribe what is best for

parents or the child or young person to do as it is the interaction of factors which is important.

5.15 Training Centre

18 year-old child diagnosed at the age of 9

'This is working well due to the good rapport with staff. My son left school with poor GCSEs. His only option was a training centre. This placement has done wonders for his day to day coping skills, self esteem and sense of identity.'

This mother implies that if his school had been able to boost his self-esteem and feelings of self-worth, then he might have achieved better academically.

5.16 Parents/carers who were not very satisfied with school

5.16.1 Parents/carers who were not very satisfied with primary school

10 year-old child

'The support is very limited and staff do not understand AS.'

11 year-old child diagnosed at the age of 7

'All the support provided by the school system has been driven by me. This has been immensely challenging and caused friction with the school. Where teachers and support staff do not understand the condition, they make mistakes in a million small ways all of which have a disastrous effect on our lives. Opportunities for him to shine missed over and over again.'

This sums up very well the many times in a day and a school week when a child may have a difficulty and the staff who do not understand AS may get it wrong. Schools are very challenging places for those with AS as they are highly social environments with demands from adults and peers that are hard for a young person with AS to meet. In addition, it seems that this child's strengths and successes were being

missed and most of the literature on AS would suggest that these have to be highlighted.

5.16.2 Parents/carers who were not very satisfied with secondary school

12 year-old child diagnosed at the age of 10

'The teachers do not really understand his condition and he has no consideration for homework. We have to spend a lot of time disseminating information, helping him to cope with the workload and keeping him emotionally stable.'

Another mother of a 13 year-old said,

'Unless the teachers are very specific, he will only do a couple of lines.'

Again these comments show the many areas which parents have to support when their child has AS – informing others about AS; getting staff to understand likely crisis points; sharing information with all the staff and helping their child's emotional well-being. This is on top of the work they have to do as parents at home, which has its own set of challenges. Time at school should be a break for parents, but often it is another area in which they have to expend time and energy, which is fine if staff are keen to work together, but very hard if parents are seen as a nuisance, or over-protective or not welcome.

13 year-old child diagnosed at the age of 8

'We have been fighting for 2 years to get her a classroom assistant. This has just been granted, but we feel two years of valuable education has been lost.'

The allocation of classroom support is often seen by parents as an essential resource to ensure that there is someone both '*looking out for their child*' and to act as translator and mediator for academic tasks. It is very hard for ELBs to estimate how many hours a pupil should be allocated. There are issues about children and young people with AS either becoming over-dependent on the CA or not wanting to be singled out as different. Some parents have said they would like their child to have the same CA throughout their school career to ensure continuity, as previous

experience has shown that good work can be undone if the new CA is not as skilled. However, there is also an argument that says children and young people need to be able to work with a number of different adults so that they get used to different personalities and styles, and have the benefit of adults who have different strengths and interests. This is also helpful when staff leave or are absent through illness. There are a number of published books on the topic of the deployment and use of Cas, and the issues which arise need to be thoroughly considered when making an assessment for the individual pupil.

13 year-old child diagnosed at the age of 6

'There is poor accommodation to my son's condition. The expectation is that he fits in, not for the school to accommodate him.'

This is a concern, as in the past many schools held the view that the child or young person should learn to adapt and cope with the way the school is. From the literature, it is clear that this is expecting too much of many with AS (and other disabilities), and that such a policy will lead to serious problems for children and young people, perhaps even exclusion. Good practice guidance on ASDs recommends that the school changes to fit the child or young person.

There will also be staff who view pupils with AS as being merely delayed or socially inept believing that they can catch up and become normal, and then do just as all the other students do. Again, this is rarely the case. Children and young people with AS are different neurologically and some situations will always be too much for the majority of those with AS to manage (e.g. very crowded, noisy situations such as canteens; corridors at break time; journey on the school bus).

13 year-old child diagnosed at the age of 12

'We had to put up a great fight and outside services had to be called in by us before they would provide any support. The SENCo said that Asperger syndrome does not exist. Recommendations had to be forced through and the school was very defensive.'

This again shows how hard it is for parents if they are not able to make the staff aware of the nature and extent of their child's difficulties. The comment about the SENCo not believing in the existence of AS is not uncommon in schools. It is a hard condition to understand and recognise, and many staff view the child as deliberately difficult and non-compliant. If the parents then appear angry and aggressive (as some parents become in their drive to get what they feel is needed), then this may serve to confirm what staff believe (e.g. 'like mother, like daughter'). In these cases, it is very important for outside agencies to join with the parents to help change the understanding and practice of the staff. There were some parents, though, who said the school did not want the Advisory Team to visit. This, then, is another issue for services to resolve.

5.16.3 Parents/carers who were not at all satisfied with school/college

Secondary school

12 year-old child diagnosed at the age of 11

'No help has been offered by the school. I told them he had AS and they just asked me what was happening next and to keep them informed. If he misbehaves, he just gets given detention or put on daily report as any other pupil.'

College

16 year-old child diagnosed at the age of 11

This father said that his son had been bullied at school and so wanted to leave, even though he was able enough to transfer to the sixth form. He was not given very good advice following school (*'there was a mix up'*) and

'so ended up on a Jobskills programme. He ends up with a lot of half days and I am not entirely sure what is offered on this programme.'

This illustrates a number of issues, the first being that some pupils will under-achieve academically because of problems at school such as bullying and will leave

prematurely to escape the trauma. For some children and young people with AS, their academic ability is their main strength and if nurtured, could lead to higher education and a rewarding career where demands and tasks they find difficult can be avoided (if the appropriate career is chosen). The second issue is that it appears that good assessment and advice before leaving school was not forthcoming, and so he did not necessarily take the best possible route after school. The third issue is the part-time nature of the programme. Some children and young people might need a less than full-time place as they would benefit from the break, and value time alone. For others, unstructured time spent at home may be fairly unproductive. It seems from the above that half days were not a choice but a given. The fourth and final issue is that the parent is not clear what the programme content and aims are. Whereas for many students aged 16 and over, it may not seem necessary or appropriate to provide these details, as the student can pass these on to parents, for children and young people with AS, it is essential that parents are involved in these discussions in order to check the potential value of this in the long-term, so that time is spent wisely and effectively.

5.17 Advice from the Careers Service

For those children and young people aged 14 or over, parents were asked whether they had received any advice from the Careers Service. One parent of a 13 year-old said she had had careers assessment but nothing had changed. Table 27 shows their responses.

Table 27: Number of parents who had received advice from the Careers Service

Advice received	Number of children	Percentage of children
Not applicable	36	61
Yes	7	12
No	13	22
Applicable, but no response	3	5
Total	59	100

Not many parents appeared to have received advice from the Careers Service and of those who did, it did not seem to figure large in their memories or experience. This service is very stretched and the knowledge of AS within the Service may not be very great. Not enough data were collected to make a clear comment or recommendation on this.

5.18 Types of support received by the parents

Parents were asked to state whether they had received the type of supports given in Table 28 and if so, how useful they had found these. In relation to medication, there was some confusion in the question as to whether this was given to the child or the parent, and so four parents annotated their reply to state that they were on medication for depression. A mother had recently been prescribed anti-depressants for mild depression by her GP who advised her *'to get a 'wee job' and to 'go home and think about whether to take the tablet's'*. She has not taken them yet. Three other mothers were taking medication for anxiety or depression

A third of the children and young people were on medication for over-activity. One 16 year child was on medication to help him to sleep. The mother of a 13 year-old who was on Ritalin said that she felt this was beneficial and helped him focus at school, and that she usually took him off this during the holidays so lessening the chance of any adverse side effects.

Table 28: Ratings by parents of help received in terms of usefulness

Type of help	Not recd.	Very useful	Quite useful	Not very useful	Not at all useful	No response
Individual counselling	44	6	3	1	4	1
Medication for anxiety/depression	44	5	2	2	2	4
Medication for over-activity	36	4	6	4	5	4
Befriender	53	1	-	-	1	4
Asperger support group	41	9	5	1	1	2

for children/young people						
Parent support group	35	12	6	1	1	4
Short-term overnight care	54	2	-	-	-	3
Activities organised	43	4	2	2	1	5
Financial allowances	28	22	5	2	4	1
Literature to read	29	17	9	-	1	4
Support/advice for brothers and sisters	46	4	4	-	-	6

5.19 Support for parents, and support groups and activities for children with AS

Many children and young people with AS talk about the relief of meeting other people like themselves and to find that, often, other people with AS share an interest and express an interest in them.

A father said,

'He was so relieved and happy to find other people like him.'

Comments on support for parents, and groups and activities for their child included:

Child aged 6, diagnosed at the age of three

Last year during the summer break, her son had been given a week on a Leisure Centre scheme from 9 to 4pm each day. This year, however, this has been cut to a week of half days only. She explained that this was her only break all summer, and that it had to be paid for. She was therefore exploring other summer activities.

This parent is not alone in requiring support, and many parents in other parts of the UK have questioned the rationale of the long, unstructured summer break for children with ASD and asked for more support from statutory services. What is most often set up is a playscheme, but parents may be asked to staff this themselves (hence no

break is achieved for them). In addition, staff of such schemes have to be well prepared and trained so that parents know their child is safe. One school in Scotland used to invite parents to bring their child with SEN and other children in the family to the school every other Wednesday evening for two hours to enable the parents to go out together (perhaps for a drink at the local pub). The children were then supervised by some staff from the school who knew them, along with other paid volunteers. The extension of such schemes to cover weekends and holiday periods would make a huge difference to parents and families.

Child aged 9, diagnosed at the age of 8

'Social workers helped with DLA, but no help from anyone else apart from school.'

Child aged 10, diagnosed this year (2006)

'I was given financial support last summer to attend football camp and for the younger child with ADHD to go to day care.'

Child aged 10

A group was set up on a weekly basis during the summer holidays for 6 sessions to work on feelings and emotions at the local Child Clinic (which her son calls the 'Wild Clinic'). He was not very keen to go, but did attend all six sessions.

Child aged 11, diagnosed at the age of 7

'I only get support from Asperger's Network.'

Child aged 11

'No one has helped.'

Child aged 11, diagnosed at the age of 7

'I have to battle for DLA every year. My main support has been another parent.'

Filling out the forms to apply for the Disability Living Allowance was mentioned a number of times by parents. These were very time-consuming to complete, and they

felt that as the child's condition was lifelong, they should not be required to fill these in so regularly.

Child aged 12, diagnosed last year (2005) at the age of 11

'Any information I have I have got myself from websites.'

Child aged 13, diagnosed at the age of eight years

'I do not feel that I have had any support at all from H and SS. Asperger's Network is very supportive and I could not do without them.'

Child aged 13 diagnosed last year (2005)

'Asperger's Network is our only support plus the private psychologist.'

Child aged 13, diagnosed at the age of 10

'A charitable organisation was meant to help him with activities outside the home, but they have failed to turn up on three occasions. The Family Fund helped towards a short holiday last year.'

Child aged 15, diagnosed at the age of 2

'I feel I had no help until he went to College. I am very isolated with him. If it was not for the College I would have no help.'

'Help from the private psychologist is very useful as there is no service available from other professionals.'

Child aged 11, diagnosed at the age of 8

'Social workers have been helpful, and the internet and our family.'

Child aged 13, diagnosed at the age of 7

'Only the Asperger's Network and PAPA have helped.'

Child aged 13, diagnosed this year (2006)

'No real support, apart from taxi drivers, teachers and escorts.'

This shows the value of those who work directly with the child or young person. Parents often have the easiest and most frequent access to these people so it is very important that the relationship is a positive one.

Child aged 13, diagnosed at the age of 8

'We have just been left to get on with it. Any support she does get is very erratic. I am studying for a qualification in ASD which has been very useful.'

A number of parents choose to take a course in ASD to further their own knowledge to support their child. Some parents then go on to develop careers in ASD or SEN. Often parents are invaluable speakers about these topics for other students. Providers of such courses need to consider the extent to which the content matches the needs of students who are also parents of children and young people with ASD to ensure they get the most from the course.

Child aged 14, diagnosed at the age of 11

'Positive Futures is the only group which offer support to my son (apart from school). This is an outing every other Saturday with other AS teenagers.'

This parent encourages the befriender to ask her son what he would like to do and also advises the befriender on the venues her son might enjoy.

Child aged 18, diagnosed at the age of 9

One parent was a social worker and said she had set up a parent support group with a social work colleague which was funded from Social Services. There was a lot of discussion on whether young people with AS were entitled to a service from a disability team, given their IQ level.

This is an issue which taxes all professionals involved in the assessment and service provision for children and young people with AS throughout the UK and a number of papers have been published on the issues arising. Neither of the two teams which are often asked to support children and young people with AS feel they are wholly appropriate. The first is the Team for Learning Disability which is designed for children and young people with below average intellectual ability, and the second is

the Team for Mental Health. This latter team is not appropriate either, as AS is not a mental health disorder per se, although some children and young people with AS will develop a mental health problem such as depression or anxiety disorder, and therefore need support from this team. Ironically, because neither team is designed for AS, the child or young person may not receive support from any agency and so go on to develop a mental health problem because they have no services, no friends, are unemployed, and have developed rigid routines and behaviours. It is essential that Health and Social Services in all areas discuss who will support children and young people and adults with AS.

Child aged 18, diagnosed at the age of 11

'We have had very little help – give us carers a break. You just have to get on with it or you go under.'

5.20 Level of understanding about ASD by different professionals, as rated by the parents

As one might predict, paediatricians, speech and language therapists, and clinical psychologists were rated as being those most likely to have a very good understanding of AS (see Table 29). For most other professionals, the ratings were mixed and was probably dependent on their training and experience of AS. Hospital nurses, orthodontists, and GP receptionists were those most likely to have no understanding of AS, although there were exceptions to this. Overall, there were more ratings in the two positive categories of 'very good understanding' (27%) or 'quite good understanding' (36%), than there were in the two negative categories of 'not very good understanding' (22%) and 'appeared to have no understanding' (14%).

Table 29: Understanding of AS by professional groups, as rated by parents

Professional	Number of parents who gave a rating	Very good	Quite good	Not very good	None	Not seen	No response
Dentist	46	8 17%	19 41%	8 17%	11 24%	8	5
Health visitor	23	5 22%	6 26%	10 43%	2 9%	29	7
GP	50	7 14%	24 48%	15 33%	4 8%	4	5
Hospital nurse	23	1 4%	7 30%	10 43%	5 22%	27	9
GP receptionist	29	3 10%	5 22%	9 31%	12 41%	22	8
Optician	34	7 21%	19 56%	3 9%	5 15%	19	6
School nurse	32	13 41%	9 28%	5 16%	5 16%	16	11
Hospital doctor	31	8 26%	13 42%	6 19%	4 13%	18	10
Orthodontist	16	1 6%	2 12%	8 73%	5 9%	34	9
Physio.	11	3 27%	3 27%	5 45%	-	38	10
Speech and language therapist	35	15 43%	12 34%	3 9%	5 12%	19	5
Occupational therapist	25	8 32%	10 40%	6 24%	1 4%	27	7
Clinical psychologist	31	14 45%	13 42%	3 10%	1 3%	21	7
Paediatrician	32	21	8	3	-	20	7

		66%	25%	10%			
Totals	418	114	150	94	60		
		27%	36%	22%	14%		

Note: Percentages refer to the percentage of parents who responded to this item

15 year-old child diagnosed at the age of 12 years

'We waited two years for an OT appointment.'

'Waiting times for services are too long. We had to wait a year for CAMHS. We have only ever seen student social workers and when they leave it can take 9 months for a replacement.'

10 year-old child, diagnosed at the age of 4

'We have very good support from other parents, but none at all from H and SS.'

5.21 Help from the voluntary sector

Literature on ASD was the help most often received, followed by parent support groups and support groups for the children and young people (see Table 30). One parent said that she felt most of the literature referred to children who had learning difficulties or behavioural problems which her child did not have. Only four parents mentioned that their child had a befriender, and two of these parents were not satisfied with this in terms of reliability or what they chose to do with their child. They felt they needed to consult more with the parents and the child or young person to decide how to spend the time. Some parents had initially had to try hard to persuade their child to attend support groups, but then their child had enjoyed the activities and continued to go. One parent of a 15 year-old, said her daughter felt the other children were younger than she was and so she did not want to attend.

Table 30: Ratings by parents on the help received from the voluntary sector

Type of help	Not received	Very useful	Quite useful	Not very useful	Not at all useful	No response
Individual counselling	41 69%	4	-	1	-	13
Befriender	44 75%	1	1	2	-	11
Asperger support group for children/young people	30 51%	15	4	5	1	4
Parent support group	24 47%	18	5	3	1	8
Activities organised	29 49%	11	9	2	-	8
Literature given	17 29%	27	5	3	1	6
Support/advice for brothers and sisters	36 61%	3	6	-	3	11
Totals	221	79	30	16	6	61

Additional comments made by the parents were:

Child aged 8, diagnosed a year ago (2005)

'We have had no help at all from statutory services since diagnosis apart from school which is excellent and PAPA which is also very good and in giving support for DLA forms.'

Child aged 16, diagnosed at the age of 11

'Asperger's Network and PAPA provide a student to take him out about once or twice a month.'

5.22 Support that parents had found most helpful

Parents were asked to rate who they felt had been most helpful. Some mentioned more than one agency. Ten of the fifty-nine parents (17%) felt that no one had been helpful to them (see Table 31). Others mentioned a particular professional (36%) or help from voluntary agencies (43%), some of which were mentioned by name, but others were not. The main reason given in favour of the voluntary networks is that parents are in the 'same boat' and can support one another and share strategies and information. Some parents said they received help after diagnosis but then it seemed to disappear. A parent of a 13 year-old child who was diagnosed at 6 years said,

'He received speech and occupational therapy for a short time after diagnosis, but has had nothing since he was aged 8. We had legal advice and crisis support during secondary transfer which was crucial. We find PAPA useful for information and have paid for private therapy.'

'The only specific support has been from PAPA, and before that from the NI Attention Deficit Disorder group.'

'All the help and advice has been through Asperger's Network. They have helped with finances for trips for children.'

Child aged 11, diagnosed at the age of 7

'Mencap helped once by having a summer camp for a week in the summer and he loved it. The Family Fund also helped us one year with a holiday.'

Table 31: Agency whom parents rated as having been most helpful

Person/agency	Number of parents	Percentage of total parents (n=59)
Professional	21	36
Voluntary group	16	27
No one	10	17
Other	5	8
Asperger's Network	5	8
PAPA	5	8
No response	2	3
Total	64	

The professionals most often mentioned were those from Education, in school or from the Advisory Service.

5.23 Comments from parents who said that the voluntary groups had been the most helpful

Seven year-old child, diagnosed at the age of 2

'PAPA is the most helpful as we all support each other.'

Ten year-old child, diagnosed at the age of 8

'Asperger's Network has supplied all support and information. It offers appropriate and useful advice, I can mix with other parents and he can mix with others with Asperger syndrome.'

Twelve year-old child, diagnosed at the age of 10

'We have had no support to date from statutory services. Asperger's Network provide seminars.'

13 year-old, diagnosed at the age of 8

'We would not be able to cope if it was not for Asperger's Network.'

Sixteen year-old child, diagnosed at the age of 12

'We find Asperger's Network the most helpful because of their genuineness and real understanding. They have time to listen and offer assistance where possible – including attending the child's school review.'

5.24 Comments from parents who said that professionals from Education had been the most helpful

Thirteen year-old child, diagnosed at the age of 10

'The Educational Psychologist has been very helpful when concerns are flagged up.'

Fourteen year-old child, diagnosed at the age of 10

'Getting him into a school that empathises with him and gives him all the support and encouragement and help they can.'

Sixteen year-old child, diagnosed at the age of 11

'The school and specially trained teachers were excellent and the speech and language therapist has helped her enormously.'

5.25 Comments from parents who said that 'other' professionals had been the most helpful

Six year-old child, diagnosed at the age of 3

'Seeing a speech therapist was our lifeline in the early days. She taught me much by how she responded to his hyper and bizarre ways in her office. Sadly, she has moved on to another area. We have not been given new appointments since her departure. He does not need speech therapy in the traditional sense any more, but he doesn't know what to say appropriately in other situations.'

5.26 Other comments made by parents/carers

Sixteen year-old child, diagnosed at the age of 8

'What is most helpful is understanding adults – there is nothing worse than other adults poking fun at your child in front of you.'

5.27 Comments from parents who said that 'no one apart from myself or family' had been helpful

Thirteen year-old child, diagnosed at the age of 11

'My own research through books and the Internet. I have found little help outside my own front door.'

5.28 Comments from parents who said that professionals from Health had been the most helpful

Fourteen year-old child, diagnosed at the age of 12

'CAMHS listened to us and didn't treat us as if we were going mad.'

Fourteen year-old child, diagnosed at the age of 11

'We have had very good support from the Clinical Psychologist and from other parents and PAPA.'

Fourteen year-old child, diagnosed at the age of 12

'Diagnosis was the most helpful as I couldn't understand why she was behaving the way she was. Now I have some answers.'

Sixteen year-old child, diagnosed at the age of 15

'The most helpful was the explanation of why she was not diagnosed earlier and frequent counselling sessions when needed (3 times a week).'

Eighteen year-old child, diagnosed at the age of 9

'It has been great to have access to a child psychiatrist when needed.'

5.29 Comments from parents who said that private practitioners had been the most helpful

As stated earlier, at least six of the parents in the sample had paid for the advice and support of a private psychologist and had found this very helpful, although expensive.

5.30 Parents’ current level of satisfaction and support

Parents were asked to rate on a scale from 1 to 10, how satisfied they ‘felt today about the level of help and support’ they were receiving (with 1 being very dissatisfied and 10 very satisfied) (see Table 32). Twenty-three parents (41%) who gave a rating were very dissatisfied with the support they were currently receiving and only six (11%) gave a rating of 10, stating that they were very satisfied. Two of these cited Asperger's Network as their main support and a third parent cited a private psychologist. The nature of the condition is such that parents are almost constantly under pressure from their child. They have to support their child outside the home and liaise with professionals who may or may not agree with what is being requested, or who may or may not have the resources. Within the home and family, they have to attempt to share their time equally with other children.

Table 32: Parents ratings of satisfaction of current services received

Rating	Number of parents	Percentage
1 (23)	B 4 NE 6 SE 7 S 6	Belfast 36% NE 35% SE 70% S 32%
2 (5)	NE 1 SE 1 S 3	
3 (8)	B 3 NE 3 W 2	
4 (3)	B 1	

	NE 1 S 1	
5 (2)	S 2	
6 (1)	B 1	
7 (3)	NE 1 N 1 SE 1	
8 (4)	B 1 NE 1 S 2	
9 (0)	-	
10 (6)	B 1 NE 1 S 4	
Total n=55		

5.31 Parents' biggest concern in living with their child at the current time (in order of age of the child)

Parents biggest concerns about children aged 6 to 9 years

'His over-reaction when things don't go his way in school with his classmates, at home, especially with the middle child, and in public. Some things I don't do on Saturdays because of his behaviour.'

'He doesn't sleep or eat properly and toileting is a problem.'

'The future and in helping him to understand his condition.'

'Coping with social skills and moving to secondary school.'

'The move to secondary school – he did not speak for 3 years in school when he entered primary school.'

Parents biggest concerns about children aged 10 to 12 years

'Their school life, lack of support, feeling of isolation, long waiting lists for help, being passed on to other services.'

'His social skills and ability to make friends, particularly as he moves to secondary school.'

'His obsession with germs and paranoia when leaving the house. No help is available for this.'

'Other people's perceptions. We were reported by a neighbour to Social Services for allowing him to play outside late at night, with a rope and not properly dressed. He needed this sensory activity to calm him down and he does not feel the cold.'

'Lack of services from Health and Education – these children are forgotten as they don't fit neatly into any programme of care.'

'Worrying about what will happen to him as a teenager and an adult.'

'As he is further isolated and rejected by peers, and their parents cut us off, he is lonely, angry and frustrated. He is on the verge of self-harming and our whole family is in great pain and conflict. As he regresses and disappears inwards, his tantrums become bigger and we all suffer more. No one cares or is there to help any of us.'

'He is very naïve and innocent and is going to secondary school where he is likely to be bullied and the teachers will not understand him.'

'Self-harm and suicidal tendencies.'

'His behaviour and he has no friends because of this.'

'His anxiety and depression.'

'Getting him to understand his condition and how others view him.'

'His future as an adult – and how he will be helped into work and accommodation.'

'Health trusts ignore pleas for help and support.'

'That he may develop mental health problems.'

'Coping with three children with disabilities and doing it alone. Being isolated. Very frustrating not being listened to properly by professionals who think they know better.'

'Educating teachers in mainstream schools so they realise the diversity of Asperger syndrome and that certain behaviours are symptoms of the condition not symptoms of bad behaviour.'

Parents biggest concerns about young people aged from 13 to 15 years

'Her lack of understanding of friendships leave her very vulnerable.'

'Lack of understanding of others. His safety. There is just not enough awareness or support.'

'Not very much help and support.'

'Bullying from peers and eating plastic.'

'Self esteem, bullying, concerns re: depression and anxiety and difficulties at school.'

'Lack of support. Education Board unhelpful and schools not educated in ASD. Lack of services and youth groups.'

'Her inflexible behaviour.'

'His lack of friends and activities, future employment and independent living.'

'Communication is very difficult.'

'Lack of respite, battles for DLA, adolescence, the future.'

'His future when he has to make his way without help.'

'She never appears to be happy – anxious all the time. We worry that she does not feel loved or needed. The future is quite frightening.'

'Showering, cleaning her teeth, washing hair. She will not go to nearby shop or make a short bus journey by herself, except on the school bus. She has no friends.'

'His safety.'

Parents biggest concerns about young people aged 16 to 18 years

'He is almost seventeen now and is pretty isolated and has no friends. He is very vulnerable. The AS group he attends is mainly for younger children.'

'His aggressive behaviour.'

'She continues to deliberately self harm and refuses to take anti-psychotic medication which reduces this.'

'Not being able to get help and advice without seeing it as a betrayal to my daughter who does not want others to know.'

'Motivating him to do chores and school work.'

'Her future – we would like people to see her good points – not constantly look for what they regard as failings, so I suppose the answer is attitudes of society.'

'Not knowing what is normal teenage boy reactions and AS.'

'Danger of setting the house on fire when cooking.'

'He has recently had psychological problems but hopefully things have improved somewhat and will continue to improve.'

'His future.'

'The future.'

'The future, although we do not look too far ahead. Relationships and pressure to get into the drink scene.'

'Getting out of the house, his behaviour and social issues.'

Two parents voiced other concerns as follows:

That the ELBs are now very short of money and that support to schools may be cut.

That there are growing numbers of children with AS and ASD and there is an emphasis on providing for the younger children.

5.32 Case studies

To illustrate some of the experiences that parents and their children have had, four case studies follow, based on discussions the Review team had with the parents. Their names have been changed.

5.32.1 Case study of an 18 year-old girl with Asperger syndrome: Emma

Emma (18) finished secondary school this term but her parents said that she received no guidance as to what she might do next. Her mainstream secondary school was not good and so her parents moved Emma into another school after her GCSEs. She was allocated 30 hours/week support, and so clearly had recognized additional needs in school. There was just one careers interview with only her parents present, as Emma does not want others to know her diagnosis or to be involved with discussions about this.

Since leaving school, Emma has tried FE locally, where the staff were well-intentioned but used the wrong approach. Emma was not given any specific support, possibly as she was deemed capable, given her mainstream school placement. However, if her previous school had been in contact with the college, well before Emma left, then her support needs might have been recognized and her needs addressed. One parent in the group said that she thought there were benefits to attending special school for this reason. Her son attended a school for pupils with moderate learning difficulties and was having a day a week at an FE college in his final year of school.

5.32.2 Case study of a 14 year-old boy with Asperger syndrome: David

David attends a very good school where staff, particularly the SENCo and the Classroom Assistant, have worked well with his parents. There was good preparation, too, before he started at the school, with maps and timetables and visits when other children were not there. Initially, and still at times, his mother has had to work very hard to get past the school secretarial staff in order to see individual staff members. At times, she says she has not passed on every concern, for fear of being seen as a nuisance. Despite her efforts and the SENCo's dedication, David has been

bullied for 2 years, from the age of 11 to the present, and the way that staff have dealt with this has sometimes increased the bullying (e.g. when staff have reported to the class that David has complained). The school staff are also supported by an Advisory teacher who has a good relationship with the school and is very useful.

5.32.3 Case study of a brother and sister: James and Ellie (12 and 13 years)

Their mother was very concerned about the support given to both of her children. This was in addition to coming to terms with the fact that they both had AS. Her son has been allocated a classroom assistant (CA) for 30 hours a week, but apparently the CA is often taken away from James to do other tasks around the school. Good practice often suggests that the CA does not stay close by the child, and works with other children, too, to discourage over-dependence, but in James's case, it seems that the CA was not available at times when James did need help. His mother also said she had not seen an Individual Education Plan (IEP) for him, although she was pleased to be invited to write some targets for her daughter's IEP.

5.32.4 Case study 15 year-old at special school: Conor

Conor (15) started at a mainstream primary school, but had a teacher in Primary 1 who did not understand him and he made little progress. He therefore repeated this year and so had two years with the same teacher. Although it was only a small class with 12 children, he did not make any progress academically. A local special school was therefore recommended by the Educational Psychologist and Conor has been there ever since. He made a lot of progress in his first few months and his mother feels it would have been better for him to have been there from the start.

He now attends a local FE college on day release. It does not seem to be sufficiently well supported, and the staff do not appear to know much about ASD. They are more familiar with neurotypical students or those with emotional and behavioural difficulties. Staff from the school go with him but are not in support all the time and there have been two incidents of bullying. Despite this, Conor likes going to College. He likes the fact that there is no uniform and that he is treated as an adult. The local ASD Advisory teacher has offered to get involved with the college if necessary, which would provide good continuity between the school and college. There are a number

of courses which he has been offered and his mother has been involved in discussing their suitability.

5.33 Life beyond school

Those children and young people with AS who had left school had often not received very much guidance in terms of future careers, nor had support or help in finding or keeping a job. A parent with an 18 year-old son with AS said he had left school and sat at home with no job. Then a supported employment scheme was set up and he gained employment and was happy and successful. However, she said that the scheme ran out of funds and so the support was withdrawn and he lost his job. He is now back sitting at home doing very little and very depressed. His mother was particularly concerned as she had another 12 year-old son with AS, whom she described as having even more problems. To her, the future looks bleak and she wrote,

'Please let others know about my situation and help me to help my wee boys.'

One 16 year-old boy with 5 GCSEs had decided to leave school after an incident where he was suspended for 'mouthing off' at a teacher who he felt had wrongly criticised him. His mother had tried to persuade him to go into the Sixth Form, but he was not keen to return. She now does not know what he will do.

Some children and young people with AS in this review had previously had interviews with Careers Advisers who were generally willing and well-intentioned but had no knowledge of AS. One parent said the Army was suggested as a possible career for his son, which he felt was inappropriate given his experiences of being bullied.

5.33.1 Supported employment for young adults with ASD

There is a pilot scheme (Employment for Autism (EFA)) which started in July 2005 in Greater Belfast and which is part-funded by the European Social Fund under the Northern Ireland EQUAL Community Initiative Programme. It is currently supporting twelve adults from the ages of 16 to 60 years with AS at present. Some students

have transferred directly from school. It is planned to work with up to twenty-four adults over two years. There are three staff, two of whom are parents of children with ASD and a part-time administrator. Autism NI, Botanic Inns and Queen's University are partners in the scheme, and can offer work experience for six to eight-week periods. Four of the twelve adults have been employed before. Initially, the main focus is to boost self-esteem. Some of the jobs which the adults would like are very competitive and difficult to get, so work is also done to move towards realistic employment. Training for adults with ASD on the scheme is done in groups, unless the person is not able to manage this, when a video of the group work will be used instead. Staff train the employers in the needs of those with ASD and suggest that they will need to alter the environment and expectations. The adults are encouraged to disclose their diagnosis to key people at work, as they are told, '*other employees cannot read your minds.*'

There are issues around benefits and at what point an adult will lose these. Currently, they are allowed to work for 15 hours a week and earn up to £80 a week, without losing benefits.

5.34 The needs of siblings

Some parents said they would like more ideas on how to support their other children, as they felt they had issues to contend with. One mother said that her daughter had commented,

'You must love X more than me – as you are always upset when something happens to him.'

Others felt regret at the constraints their child placed on the family (e.g. holidays; joint activities; visiting friends; shopping) because of what the child with AS could do or would or would not tolerate. There are now a number of books written for siblings, and workshops have been developed for siblings to enable them to raise and discuss issues.

Section 6: FINDINGS
Data from Schools and Colleges in Northern Ireland

6.1 Introduction

Every mainstream school, special school and college which had students aged from 10 to 18 on roll was sent a short questionnaire to complete (see **Appendix 5**). This sought data on the numbers of students with AS/HFA on roll, if any, the support given and received and the improvements seen in the last three years.

In addition, data collected from schools by the Department of Education in Northern Ireland were analysed. These were presented earlier.

A total of 1102 questionnaires were sent out and a total of 205 were returned (i.e. 19%) (see Table 33). This is a low return rate for a postal survey. The two main factors potentially affecting the rate of return are firstly, that if a school or college does not currently have a student with AS or HFA, then respondents are unlikely to return it and secondly, that as the schools are asked to supply these data to the Department of Education, they may have felt this information was available already.

Table 33: Number of questionnaires returned by region

Board	Number of schools/colleges	Percentage of the total returned
North East	55	27
Southern	42	20
South East	41	20
Belfast	31	15
Western	29	14
Not given	7	3
Total	205	100

6.2 Type of respondent

Over half (61%) of the questionnaires received were completed by the Special Educational Needs Coordinator (SENCo), and a fifth were completed by the Principal of the school (see Table 34). Clearly, the responses will be affected by how well these respondents knew individual students with ASD and the support they received.

Table 34: Person completing the school/college questionnaire

Role	Number completed	Percentage
SENCo	125	61
Principal or Headteacher	45	22
Combination	27	13
Not given	4	2
Head of LS	2	1
Deputy	2	1
Total	205	100

6.3 Number of years that the respondent had worked at the school/college

Most (64%) respondents had worked at the school/college for over 10 years and, therefore, were likely to know the pupils and provision very well (see Table 35).

Table 35: Number of years that the respondent had worked at the school/college

Number of years	Number of respondents	Percentage
More than 10 years	132	64
6-10 years	35	17
3-5 years	19	9
1-2 years	9	5
Less than a year	2	1

Not given	8	4
Total	205	100

6.4 Overall tone of the responses

Overall, the tone of the replies was very positive and almost ALL schools and colleges which had students with AS could point to improvements over the last three years, both in terms of what they were able to do, and in their understanding of the condition. This appeared to be the case across the five ELBs.

The key areas that staff identified which had improved were:

- Knowledge and awareness of the condition and its implications for the child and the parents;
- Opportunities and availability of training both in school and externally;
- Much closer working together with parents and a desire to collaborate more;
- The value of autism advisory services – almost all said these were very useful and that they would like more; and
- The value of Classroom Assistant (CA) time.

It is not possible to identify the reasons underlying these developments, as there are several possible factors involved. These include greater public awareness of ASD from the media and the internet, in addition to the increase in training opportunities provided by the statutory services, voluntary organisations such as Autism NI, and Higher Education institutions. It is likely, however, that some of these improvements stem from the work of the relatively newly-established ASD Advisory Services in each of the five Education and Library Boards.

6.5 Support from Classroom Assistants

In discussion with parents, many said they would prefer their child to have the same CA throughout the time allocated if possible. This was summed up by a parent who said,

'If there was ONE thing we would like, it is a good CA throughout their school career. He can have a great year and then be followed by disaster and then we get terrible tantrums at home. If the child is well supported at school, then parents have a much easier time at home and the child learns'.

However, CAs often report that it is extremely emotionally tiring to support the same child all the time in that they feel over-responsible for the child's performance and behaviour. In addition, there are likely benefits to the child in having more than one adult. Adults have different skills and personalities, and it may be helpful for the child to learn to adapt to a number of different adults so they can manage better if a CA is absent from school.

In the case of Ellie, her mother said that she was bullied by other girls using MSN chat, and that she felt the staff had made it worse in the way they had dealt with it. She phoned the school at times, but often her calls were not returned. She would have liked a home-school diary to be completed every day for her children (and other parents in the group said they would have liked this, as their children found it very hard to communicate about school issues). Some reported that the primary school staff were more willing to do this than secondary schools. One secondary school agreed to write a weekly report on Fridays which was much appreciated.

The mother of a 13 year-old said that he had a wonderful CA who went on training courses at her own expense.

6.6 Training issues

Several respondents referred to the fact that they had learned and developed their expertise by working with the student in the school. It is interesting to ponder how much impact training has, if a teacher or CA has not yet met a child with AS. Clearly, most parents and Headteachers would probably say that they would like the child to be taught by a teacher who is already trained and experienced. The reality is, however, that many teachers in mainstream (and in special) schools will NOT have knowingly taught a child with AS before. They therefore have to learn '*on the job*' and '*on the child*'.

Some readers will be familiar with the following question:

If you needed brain surgery, would you prefer to be operated on by a surgeon who was trained:

- (a) Before
- (b) During, or
- (c) After the operation

Clearly, all would answer BEFORE the operation. That said, surgeons will have learned and developed their skills by observing others and whilst operating, and will become more skilled with experience. Ideally, teaching staff would be able to spend time watching other teachers, CAs and experienced staff and parents working effectively with children with ASD.

An alternative, which is more cost- and time-effective is to watch videotapes and DVDs and a number of respondents had done this. A number of videos and DVDs are now on the market for this purpose, some of which have been developed in Northern Ireland (see the list of Resources at the end of this Review). Some of these resources will be more useful than others, and it is important to use these with the same degree of critical judgement as with other ASD resources, from literature to the internet. In addition, some materials focus on children and young people with AS, while others focus on those with ASD and learning difficulties. Some resources concern Education and staff working in special schools, and others have a focus on

inclusion in mainstream schools. Yet others focus on the identification and diagnosis of ASD and are directed at professionals in Health.

It would be preferable for all teachers and classroom assistants to have some training and information on AS before they started to work with the child, and there was evidence from some respondents that this had happened. Some teachers and CAs are able to learn very quickly, as do parents, in how to understand and manage the child effectively, and so there are staff who have received no formal training but yet who are very skilled.

As one father said,

'The Headteacher was fantastic. He didn't have any experience but he was genuinely fond of my son. They had to make a rule about asking questions in class as he asked so many. He had to stay quiet for 10 minutes each time he had asked a question.'

6.7 Training courses

There are also many different training courses available in terms of content, delivery, venue, frequency and number of sessions. When resources are scarce, then good decisions need be made on which course to attend. The West Midlands region in England has recently produced a Training Framework (FREDA and Jones, 2006) against which both training providers and the participants can map the training they provide. It is hoped this will help to plan and provide training more effectively. It may be a useful exercise to conduct within Northern Ireland.

6.8 Extent to which the needs of students with Asperger syndrome are met

Many replies from school and college staff were very positive in that they showed a real willingness to want to know more and to change practice to better meet the needs of the students with AS, and this was very heartening. Eighty-one per cent felt they met the children's needs very well or quite well (see Table 36). Almost without exception, respondents said they received outside support and guidance from an external agency, most usually from the relatively newly-established ELB ASD

Advisory Teams, but Educational Psychologists were also mentioned and training events offered by Autism NI (PAPA). It may be that Headteachers and SENCOs who completed the questionnaires wanted to reflect well on the school and college and so gave positive responses. The teaching staff working with the students might have given different replies.

Table 36: Extent to which the needs of students with AS were met, as rated by the schools and colleges

Extent to which needs met (n=86)	Number of schools/colleges	Percentage of 86 respondents
Very well	24	28
Quite well	45	53
Not very well	6	7
Depends which pupil	10	12
Not applicable	120	-
Totals	205	100

Sixty-five (76%) of the eighty-six respondents with students with AS or HFA on roll said that they received advice to support the student with AS, seventeen (20%) said not, and three did not respond to this question.

Respondents were asked to comment on whether staff felt the school placement was appropriate. Fifty-one (60%) of the eighty-five respondents from schools with students with AS or HFA on roll said ALL staff felt it was appropriate, thirty (35%) felt that only SOME of the staff thought it was appropriate and only two respondents said that NONE of the staff felt it was appropriate, believing instead that a special school placement would be easier for the student.

This Review and the arrival of the questionnaire could have been an opportunity for schools which felt very under pressure and dissatisfied with the support for students with AS to voice their concerns, but only a small number felt they were unsupported.

It may be that schools did not KNOW what else they might be doing to support the student and so felt satisfied. This is always a difficulty when asking questions about

the extent to which needs are being met, that is, one does not know what one does not know. Nevertheless, the Autism Team at the University of Birmingham has been involved in several reviews of provision and has often received many more 'negative' reports from school staff who feel they are not sufficiently supported and find it very hard to effectively teach these children. This was not the case for most questionnaires received. That said, of course, many respondents could identify areas for improvement. The main suggestions for areas to improve were as follows, in order of frequency:

- Training for ALL staff
- More one-to-one help for the child
- A quiet area or room in the school for the child to have a break

6.9 Differences of opinion between staff and parents

Overall, the vast majority of respondents were keen to seek more time with parents, and acknowledged the very difficult job that parents had. A few respondents said they did not agree with the actions or decisions of the parents about the child – most often to do with their reluctance to go for assessment, or to share the diagnosis. This is a very difficult issue for all. Parents have the right to act as they see fit in relation to their children (provided they do not harm the child emotionally or physically). There are those parents who have had very difficult and upsetting encounters with professionals before and during diagnosis and/or in the early years at school. It is understandable that they do not always feel they can trust what other professionals (i.e. school staff) might suggest. Clearly, too, the parents' course of action might be the better course to take. Issues regarding the discussion of diagnosis with the student and his/her peers are complex (Murray, 2006), and there is not always a clear-cut answer or route to take.

The Disability Discrimination Act Part 4 (2005) is very clear that informed consent must be obtained from the child or young person before any information about them can be shared with a third party. This is absolutely non-negotiable. Therefore, any

ideas from staff or parents on discussing the needs or behaviours of a student with AS with their peers, parents, or other staff or agencies cannot proceed without the consent of the child or young person (Martin, 2006). Ideally, decisions are reached on the basis of good information and in discussion with all involved parties. Some respondents said that they wished they had more time to spend in discussion with parents. It is then more likely that a consensus is reached. Where a teacher or a parent is not persuaded by an argument, then it is not good practice to force the issue. Instead, it is sometimes necessary to wait until more evidence to support a view can be obtained or shared. Some diagnosticians in the field of ASD and other conditions do not give the diagnosis to the person or the family until they are ready to take this on board.

One teacher said she felt that some parents were too demanding of the staff, even when they (the parents) acknowledged there were another twenty-nine children in the class. The relatively positive data from the schools does reflect, to an extent, the comments made by parents, who most often mentioned the school as being the most helpful agency, although a significant number of parents were also very critical of some of the schools their children had attended, and some parents had chosen to move their child because of this.

Many replies showed an appreciation of the heavy demands on families. Some suggestions made by school and college staff therefore recommended improvements to services for families. These included the suggestion that there should be more respite care, a database of services and information on ASD for parents, and more out-of-school activities for the children and young people with AS.

It was very interesting and of some concern that none of the respondents mentioned bullying as a problem, and yet this was the most often cited difficulty by the children and young people and by some of their parents. There were some references by some staff to the importance of educating other children in the school about children who were different, but no reference at all to the importance of anti-bullying policies or measures.

In the ETI (2001) survey, it was reported that most of the bullying appeared to occur in the playground and in free time which was unsupervised by staff, and that it was often done by pupils who were not in the same class as the pupil with AS. This might go some way to explaining why staff in this Review were not aware of this. Clearly, it is important in staff training to create awareness and to suggest that bullying is very likely to occur, so interventions need to be put in place to prevent and deal with this.

6.10 Age range of the students who attended the schools and colleges which returned the questionnaire

Most of the pupils at the schools who returned the questionnaires were from the primary age group. This may explain the positive responses received, as many would predict that secondary school is a harder setting for a youngster with Asperger syndrome (see Table 37).

Table 37: Age range of the students who attended the schools and colleges which returned the questionnaire

Age range	Number of schools/colleges	Percentage
5 to 11 years	128	62
11 to 16 years	10	5
11 to 18 years	38	19
5 to 16 years	2	1
5 to 19 years	4	2
Other	16	8
Not given	7	3
Total	205	100

6.11 Number of schools/colleges with children with Asperger syndrome

Just under half the schools/colleges which returned the questionnaire had one or more pupils with AS on roll (see Table 38).

Table 38: Number of schools/colleges with children with Asperger syndrome

Number of children with AS	Number of schools/colleges	Percentage
None	111	54
1-5 children	79	39
6 to 10	5	2
More than 20	2	1
Not given	8	4
Total	205	100

One school in the WELB area commented that the local diagnosticians do not distinguish between these terms and tend to use the term ASD. They identified fourteen children on roll from a total of 872 at the school.

6.12 Number of schools and colleges with pupils with high functioning autism (HFA)

A smaller number of schools reported that they had pupils with HFA on roll (see Table 39).

Table 39: Number of schools and colleges with pupils with HFA

Number of children with HFA	Number of schools/colleges	Percentage
None	160	78
1-5	27	13
9	18	9
Total	205	100

6.13 Number of schools and colleges where respondents suspected some pupils had AS or HFA, but they had not been diagnosed

There were 61 schools or colleges where staff felt that there were pupils on roll who might have AS, but who had not received a diagnosis (see **Table 40**).

Table 40: Number of schools and colleges where respondents suspected some pupils had AS or HFA, but they had not been diagnosed

Number of children	Number of schools/colleges	Percentage
None	130	63
1	35	17
2	18	9
3	3	2
4	3	2
5	1	-
6	1	-
Not given	14	7
Total	205	100

One secondary school said they had a pupil who they suspected had AS and had requested that the Statementing process be started over a year ago, but as yet no support had been provided. Another grammar school said the parents of one child were resistant to school intervention.

One school suspected they had three children under the age of 10 with an ASD diagnosis. One SENCo in a post-primary school said,

‘We think there may be two pupils with AS not diagnosed. They are often not diagnosed in the primary sector and then when they are in the secondary sector they are not receiving proper support.’

This respondent also wrote,

‘Whilst I have no doubt that we have several children on the autistic spectrum, at least two of them with AS, the parents refuse to have the children formally

assessed and diagnosed. Diagnosis is seen as both a threat to the parents themselves and also of no value to the child who may simply be seen as gifted or withdrawn.'

This relates to the point made earlier about issues arising when staff and parents disagree on the course of action taken.

6.14 Staff qualifications and training in ASD

In terms of staff qualifications, eighteen (21%) of the eighty-six respondents reported that staff did have qualifications in ASD, sixty-three did not and four did not know. Seventy-five (87%) respondents said that they had received some training in ASD, eleven had not and the rest did not answer this question. These figures are encouraging, as the majority of respondents have stated that some training has been received and a fifth of schools had a member of staff who had done some intensive training leading to a qualification. Five years ago, it is likely that only a few staff would have had any formal input on ASD.

6.15 Examples of good practice in ASD

Nine schools (10%) felt they had some good practice in relation to children with AS and HFA, 33 schools thought they might and 34 felt they did not have anything to report on this. One SENCo showed an awareness video on AS to staff, and another was writing a thesis on extra curricular activities, the development of social skills and how to manage stress and anxiety.

6.16 Consultation with children and young people with Asperger syndrome

In terms of consultation, twenty-five respondents (29%) felt that they consulted pupils very well, and forty-two felt they consulted on some issues. Seventeen respondents (20%) felt they did not consult very much, and two said they did not consult at all with students with AS.

6.17 Comments on the advisory support provided to schools on meeting the needs of the children and young people with Asperger syndrome

Sixty-five respondents (87%) said that they received support in terms of advice for the child with AS, 17 said they did not and three did not respond to this question.

In terms of having extra adult support from a Support Assistant, one respondent at a college said,

'My experience is that students do not want support which differentiates them from their peers. How well a student's needs are met depends on the teacher, the course team and parental support. The student access and support officer gives staff information on AS. All except one are on vocational courses and they have problems in producing their portfolio but are often helped by parents and staff. The one student following an academic course has refused support and I do not feel he will get the results he expects.'

Comments from respondents were classified into three groups: those which suggested staff were satisfied with the support they had received and were able to give to the student; those where staff were reasonably happy but could point to some areas which could be better; and those who did not feel they were meeting the needs very well at all. Overall, there were more wholly positive replies than otherwise, often due to the provision of CA support and/or advice from the Advisory Team. The comment made by one respondent, that problems are inevitable when a student with AS is placed in a school environment, is very telling. It is one of the most challenging environments within which the student has to operate, because of the huge social demands and sensory issues and it is compulsory. Many adults with AS and ASD graphically describe the problems they had at school. It is therefore the responsibility of all who work within a school or college to acknowledge these difficulties as a given, and to do all they can to help, support and counsel the student with AS.

The comments from respondents are given below in the three satisfaction categories, and give details on the type of extra support that was provided:

6.18 Respondents who were satisfied with the support

'We have an effective pastoral learning support team which contributes to the needs of this student.'

'The pupil has a CA and a laptop and two free periods to work with the CA and receives extra time for exams.'

'Both students are making excellent progress which is very pleasing as one student had been out of mainstream for a whole academic year.'

'We have received specialist training on how to support her from ASD advisory services and the adviser has worked individually with the pupil.'

'Additional time agreed for GCSE, exam prompting and separate supervision.'

'CA has been supplied for one pupil.'

'Pupils have CAs or are placed in small classes and taught by staff who have experience of learning difficulties.'

'All teachers are aware of the child's problems. A specialist has spoken to the staff about the condition. The child had an IEP which is reviewed regularly.'

'One pupil found transition to secondary school very traumatic, but with 10 hours CA he is now managing extremely well. Another pupil is not able to go into mainstream lessons so attends the school support centre for mornings only.'

'One student has a CA who is developing his social skills, and we have regular meetings with parents and the staff have had training.'

'This has improved with experience and the support given by the ELB ASD service.'

'The two children have a CA and there is an outreach teacher for staff.'

'A CA is provided by the ELB and there are only 22 in the class.'

'His needs are well met as we have excellent parental support.'

'All staff have had training and two are TEACCH trained.'

'Very good support. He has a CA and regular reviews and he is well liked.'

'He has made very pleasing progress due to the efforts and understanding of staff plus significant parental support and engagement at home.'

6.19 Respondents who were reasonably satisfied with the support but could point to areas for improvement

'Schools are doing everything in their power but parents are wanting more.'

'Staff work hard to meet needs but additional training specific to AS would be valuable.'

'The staff and parents are happy with progress but there has been very little in terms of staff training or in finding experienced CAs.'

'There is huge variation in pupils. There is an inevitability about problems when a huge organisation clashes with the needs of a young person with ASD. This school has over 800 students on roll.'

'This depends on whether other conditions are present (e.g. ADHD).'

'All 6 pupils have CAs, but it is not possible within our school to have a restricted timetable.'

'Most of the 7 students we have are happily settled.'

'Some find moving around the school difficult.'

'The five pupils are supported by withdrawal classes for social development, but this only scratches the surface of what they need.'

6.20 Respondents who were not very satisfied with the support

'We don't feel we meet his needs very well. A Statement has been refused by the ELB and he has remained at Stage 3. The school is struggling to support him.'

'We need support from an adviser and some hands-on support.'

'The lack of funding and very tight budget reduces resources which may improve provision.'

'Not very well supported, as yet – we are awaiting funding.'

6.21 How might schools and colleges better help students with Asperger syndrome?

Respondents from the colleges said they would like more information from schools. They commented that some parents want a clean slate and so give very little information on their child to the college staff. Other parents pass on lots of information. One respondent said he would like advice from the school on how best to work with the family of the student, and another said he would like to see an extension of the Behaviour Support Service in ELBs to Further Education. Finally, another college respondent said he would like more awareness-raising for staff to *'reduce the fear of the unknown'*.

The responses from schools were grouped by theme. The majority of respondents from schools had suggestions on how students might be better supported. Twenty-three (53%) referred to more awareness training for staff; six (14%) wanted more advice on specific strategies; and five respondents wanted either more CAs, more advisory time or a specific resource. Resources mentioned included a safe haven, a sensory room, and ICT. Other ideas mentioned included advice on students with AS who were bilingual, more out of school activities and improved provision post-16.

6.22 Comments on the support received

Seventy-one respondents commented on the nature and value of the support they had received from external sources. Forty-eight of these mentioned the very good support they received from the Advisory services using terms such as 'first rate' and 'excellent', and nine mentioned the support given by the Educational Psychologist. Some telephoned as well as visited. The support given included advice on strategies, training for staff and help at transitions. A few felt that the visits were not frequent enough to be helpful and wanted more ongoing support. Other agencies mentioned less often were the Behaviour Support Service, Clinical Medical Officers, Autism NI and Asperger's Network. One respondent from an independent school which was not eligible for support commented,

'As we are an independent school, the Boards focus on its schools rather than on its children, and refuses to fund any help for the children we have, even when the EP feels the child needs a CA. To some extent it is the coping skills of the teacher and the rest of the class that determine how well a child's needs are met. As the class sizes are small it has generally worked, but if there is more than one child in the class it does not.'

Other staff commented on the fact that the advice is useful but sometimes hard to implement, for example,

'Useful information passed on but sometimes the reality of the classroom makes it hard to take everything on board. Advice to the CA the most useful as they can monitor the situation.'

6.23 Improvements seen by respondents in the last three years

One college respondent said,

'Most, if not all, staff teams are keen to work with these students and their families. There is definitely a wider awareness of AS and many myths have been dispelled. There is better learning support and a greater awareness of its availability.'

Similarly, another college respondent said,

'There is much more awareness of the syndrome and much more acceptance of disabled students.'

For respondents from schools, seventy-three (82%) of the eighty-five who had students with AS on roll said they had seen improvements over the last three years. Thirty of these mentioned increased awareness amongst the staff and twenty said they were better supported. Other comments made referred to changed attitudes and the use of specific strategies and resources. The first three comments refer to the valuable experience it has been for the school to have a child or young person with AS.

Comments which highlight useful points are as follows:

'It was a big change. We had never had any child with an ASD before at the school and it was a learning curve for both the school and the child but we worked together getting a lot of support from home and it has proved a success.'

'The staff know of AS and are coping very well. CAs no longer have any fear of the condition and there is great communication between the parents and school.'

'There is increased staff awareness of AS and staff attitudes have changed. They are more positive and less stereotyped as a result of teaching this student. ASD is no longer classed as a "special school only" issue.'

'The Autism Advisory service did a session with ALL staff present which was very useful and we also had support from the Family Clinic. Not all parents want the assistance of the Autism Advisory Service and may see them as interfering, but we have shown parents the benefits.'

'There is more awareness of the authenticity of these problems and the futility of labelling "sufferers" as bad children.'

'Raising awareness in staff and pupils becomes a positive asset to what the school offers. Good practice in ASD transfers to other pupils with needs.'

There has been a significant increase in the number of children with an ASD identified. This has led to an increased demand for training and support to schools and colleges. In one ELB, for example, when the support teacher was appointed, there were just twenty-eight pupils on her caseload (from 500 schools). Three years later, there are now 250 pupils with ASD to support in mainstream schools, most of whom have a Statement of SEN. This service receives about twelve to fifteen new referrals a month. Pupils can be supported by the service at Stage 3 of the assessment of the Code of Practice, and staff in schools can be advised on pupils at Stages 1 and 2. This Advisory Service also has thirty children at the transition stage from primary to secondary school and so the level of support they can give on this is quite low.

Respondents on the school questionnaires commented that these staff used to be able to visit schools fairly frequently, but now, because of growing caseloads, they have had to reduce this and waiting times have got longer. Such increased demand

needs to be taken into account in forward planning and resource allocation. It also means that staff in the Advisory services have to focus most of their time on giving advice and resources to SENCOs and key-workers in schools, as it is they who are going to do the 'hands-on' work.

6.24 Negative comments about support provided for children and young people with AS

There were only four respondents who replied negatively to the question about improvements seen in the last three years. Their comments are as follows:

'There appears to be an increase in numbers, but unfortunately the Board's support service for ASD has not increased to the same degree, which leads to longer waiting times and a decrease in the number of visits. Their advice is vital.'

'Good training is available but the funding is not there to allow staff to attend.'

'Government policy of inclusion is laudable, but necessary structures and resources are needed if other pupils are not to be discriminated against.'

'There is a huge waiting list so some children may have to wait 18 months before any consultation from the Advisory service, during which time you are left to your own devices, and we can wait 3 years for a medical diagnosis to be given.'

6.25 If you had three wishes in relation to the support for children and young people with Asperger syndrome, what would they be?

Many respondents mentioned the same types of support as above, but there were some additional ideas. Some spoke of the consistency that was needed throughout the whole school or college in terms of understanding and practice. One said that he wishes that people did not make assumptions about these students which prevented their participation in activities. One suggested there was a need to educate the

general population so that parents did not feel criticised and would therefore be more prepared to seek help. Another stated that he wished that where,

'a child is having real problems with his peers, then it is cruel to keep him permanently alongside them.'

A similar comment was made by another respondent who said he wished,

'staff would avoid situations which cause the child stress and agree to give them time out with their favourite thing or activity.'

One felt it would be good to be able to have direct referral to some external agencies to cut down the waiting time, and another felt there should be a parent support group in every town or local school.

There was a comment, too, about the current regulations regarding the Transfer Procedure tests, whereby some children with a diagnosis are dealt with differently. The respondent said,

'The only negative I have to report is the way he was not allowed to take part in the Transfer Procedure tests in the same way as his peers. He took the tests under the condition that they would not be marked. In practice, he scored high and higher than those children who achieved Grade A.'

This was also raised by parents who said they deliberately delayed getting the diagnosis until the child was aged over 11 years to avoid this.

Finally, one respondent in a secondary school wrote,

'I honestly believe we have gone a long way to ensuring the wishes of consistency, good relationships between staff, parents and the students and meaningful social and academic activities.'

6.26 Comments from parents and others about school/college practice

For parents, school or college was often the only area of life where they felt the child was being supported, although some had had to change their child's school or college placement because their first choice had been disastrous. Some schools were reported to be good in parts, usually because of a knowledgeable or enlightened member of staff such as the SENCo, the Head of Year or Headteacher. The main improvements mentioned were: much better awareness of ASD amongst staff, more training opportunities and the greater involvement of parents in discussions. Some respondents in Health reported that secondary schools varied in their ability to differentiate and in their attitudes to inclusion and SEN generally. Some schools allowed the children and young people to have a lot of breaks and to have a modified timetable.

SECTION 7: FINDINGS

Interviews with professionals from Health and Social Services

Interviews with health professionals

Face-to-face interviews or telephone interviews were held with two clinical psychologists, two paediatricians, two independent psychologists and two social workers with special responsibility for ASD. In addition, a member of the Review Team joined the Special Interest Group (SIG) discussion on diagnostic issues held at the Autism NI offices in April 2006. The SIG group had twelve representatives from all four health boards. A member of the Review Team also joined a multidisciplinary meeting convened by one of the Health Boards where ten representatives from Health, Education and Social Services volunteered their views on services for AS. The data which follow are taken from these interviews and discussions (see **Appendix 6**).

7.1.1. Diagnostic issues

Both clinical psychologists (CPs) interviewed felt there was a need for specialist posts in ASD, as work on ASD was being added to the roles of Clinical Psychologists, but other responsibilities were not being taken away. Referrals of children and young people mainly came from School Medical Officers, some of whom had been trained in using ASD diagnostic instruments, such as the Autism Diagnostic Interview-Revised (ADI-R). One of the Consultant Clinical Psychologists interviewed had almost finished her accreditation as an ADI-R trainer, and the plan was then for her to train two paediatricians to use this and then to train other professionals in the future.

At the SIG group it was reported that waiting lists to be seen by Clinical Psychologists can range from 12 to 18 months, and if a CP develops a specialism in ASD, then they often receive many more referrals from colleagues. Those on the waiting list might be seen by other professionals, but may not have the diagnosis confirmed, so the parents and the child might be left in limbo.

Generally, a child or young person referred for assessment would be seen for a half-day assessment, during which there would be a developmental interview using the ADI-R or Diagnostic Interview of Social and Communication Disorders (DISCO), and the when Autism Diagnostic Observation Schedule (ADOS) might be used. Some psychologists would also use an intelligence test such as the Wechsler Intelligence Scale for Children (WISC-III-R). Prior to this, reports from all the people who know the child would be requested (e.g. Educational Psychologists, teachers, speech and language therapists) and some CPs would observe the child or young person in school.

After the assessment, CPs will give the parents the diagnosis. They will ask parents whether they want to tell their child (if aged 16 years or under), or if they are 17 or 18 years old, the CP will tell the young person, unless the young person has current mental health problems and it is thought inadvisable at the time. It is the parents' decision as to whether to tell their child. One CP also gives the parents Carol Gray's *Sixth Sense* to read (Gray, 2004).

Some parents in this Review said that they rarely had time to speak to professionals for long enough, or without their child present. One mother said she was told when her son was 6 years old, '*He has got this thing called autism and there is no cure for it.*' She said she felt completely floored and depressed, as his behaviour was very difficult at the time and she left feeling that her situation was long-term and hopeless. There were at least six mothers in the review whose partners were choosing not to recognize that their son had AS. This caused real problems for the mother and increased their stress levels as they felt unable to attend meetings or to bring literature into the house. One mother had made a folder on AS for her husband but he never touched it. He blames his wife for seeking diagnosis and will not accept the professional's view. One Clinical Psychologist said he felt that some families with a child with AS would welcome and benefit from a continuous keyworker after diagnosis to monitor and coordinate services to the child or young person and the family.

After diagnosis, one CP would see the family again eight weeks later (maybe the parents only or with the child or young person) for a Question and Answer session, and tell them about support from Autism NI and the National Autistic Society. There is also a relatively new booklet which might be given out, created by Lisburn and Down, with questions and answers on Asperger syndrome. This eight-week appointment usually has to be their final one, but parents can ask for help from other basic grade psychologists with particular issues.

This CP said,

'Ideally, I would like them to be able to keep people on the books, but I have to tell them that I am not able to continue with interventions, unless they specifically request this later. We have no manpower to do this work.'

To address this shortfall, this Health Trust have put on Parent Workshops for all parents with a newly-diagnosed child in the last year. There were five sessions run on a weekly basis (on Thursdays from 9-30 to 4.30pm). It was felt that as many parents work, it was easier for them to take a day off, than to come to evening sessions.

This summer, the Trust is running workshops for children and young people, as parents now say, *'There is more for us, but little for the children.'*

Two separate groups will be held, one for primary children and one for secondary aged children, with about 10 to 12 children in each. These will run every Thursday during the day, organised by a basic grade psychologist and a trainee psychologist, with supervision. Priority will be given to those children and young people diagnosed last year. In their experience, children and young people are often very tired, so after school clubs may not be as successful.

After diagnosis, one clinical psychologist who does some private work said that she would usually do a follow up appointment with the family and refer them on to professionals. She said that there are not very many services to refer on to, but she would usually refer on to the Educational Psychologist and/or the ASD Advisory services. She has found that the parents' main concerns are not on daily living, but

relate to the children and young people's experiences at school. This psychologist felt that not all need a Classroom Assistant, but that all would benefit from having a mentor in school who they can see on a regular basis, two or three times a week to debrief.

In terms of literature, this psychologist did not use any published leaflets or books. She preferred to write her own account based on the child or young person. Once she has written the diagnostic report, she goes through this section by section with the parents and sees this as a very useful and educational process for them.

7.1.2 Waiting lists

Waiting lists for a full diagnostic assessment can be over two years. The older children are usually given priority and then the very young children. During the waiting time, schools can be given advice and the child may be seen by the Speech and Language Therapist (SALT). In one Health Board, there are currently 100 children and young people on the waiting list. The team conducted 50 diagnostic assessments last year across all age groups. Some areas are now trying to do group assessments, to work through the waiting list more efficiently. Several children attend a group over a period of four to five weeks for two hours and diagnostic data is collected. The parents are in an adjoining room where they can talk or discuss issues with a speaker or in some venues, watch the child by video link. Professionals involved meet once a month to decide which children should be grouped together, and the SALT might make visits to schools to observe the children. Children are usually grouped by age and to date, all ages up to Primary 7 (age 11 years) have been seen on a group basis. Permission is sought from the child's parents to send questionnaires to professionals who know the child. For some children, the diagnosis can be made fairly quickly, but for other children with more complex histories and behaviours, the process takes longer. The DISCO and ADOS might be used to aid diagnosis. Several parents in the sample had paid for private diagnostic assessment and, in some cases, for private counselling sessions for their child to get around this problem. This was expensive but most felt this was money well spent. This happens elsewhere in the UK too, and there is likely always to be a market for independent and private work, but as statutory services improve, then the need for this will decline.

7.1.3 Databases kept by health and other agencies

(FINDING 3 in the Executive Summary)

The needs arising from AS may require support from Health, Education, Social Services, the voluntary sector or all four, and so different lists of children and young people with AS will be held within agencies often in different formats and with different criteria for inclusion on the database. Currently in Northern Ireland (as in most places in the UK), databases are not shared between agencies. Often, even within an agency, there is no one person who has access to all the data on a particular group of children and young people, in this case AS, and so gathering data is difficult. One CP said that she kept her own database as it was more reliable. She said,

'The database is very frustrating. It is hard to access data you want so my secretary has created her own. We often end up doing hand counts.'

Time and money is potentially wasted in having several databases. Having one central database that all can share would aid planning and resource allocation. However, there are some serious ethical and logistical issues to resolve which is why many professionals have not made much progress down this road.

This situation is true for most areas of the UK and work is underway in some areas to address the problem, and to try to create one database for all to use. There are ethical issues about disclosure and confidentiality, and in relation to the competence of different professionals to assess and diagnose Asperger syndrome. To discuss some of the issues surrounding diagnosis, a Special Interest Group (SIG) meets twice a year at the Autism NI offices. This is a very useful group as it is the only forum where health professionals from all four Health Boards get together to debate practice and policy issues around professional and practice development. Case studies and professional journals are shared, and a speaker might be invited. The SIG has identified ongoing training needs and has spearheaded the introduction of specialized diagnostic training in Ireland (e.g. in DISCO (Diagnostic Interview for Social and Communication Disorders) and ADOS (Autism Diagnostic Observation

Schedule), in partnership with Autism NI). The SIG has also issued a 'Gold Standard' for private diagnosis in Northern Ireland to introduce try and introduce excellence in Northern Ireland.

7.1.4 Interviews with paediatricians

One paediatrician, who worked as part of a multi-disciplinary team including an Educational Psychologist, felt that diagnostic practice had improved over recent months in their area. She spends five half days a week on the assessment of children with ASD. She said that,

'the big increase in referrals in the recent past is now starting to level out and schools now are much better with these children'.

They had tried using Checklist for Autism in Toddlers (CHAT) with health visitors for screening purposes, but this has not been adopted generally.

Once a diagnostic assessment is completed, there is an assessment team meeting between the EP, SLT, paediatrician, parents and the SENCo who all discuss the diagnosis. Some of the older children might be involved, and one paediatrician commented that they appeared to enjoy the experience. After diagnosis, parents are given a one-page summary sheet which is also given to other professionals, with the parents' consent. The social worker makes contact with parents within a week of diagnosis to follow up. The EP is seen as the route into the schools. Diagnosis is only made if all parties agree with it.

In terms of written information, one paediatrician gave NAS leaflets on AS and Tony Attwood's book on AS (Attwood, 1998) which is quite light-hearted, optimistic and practical. Another useful book for teachers is that by Matt Winter (2003) entitled, *Asperger syndrome: what teachers need to know*. In addition, Autism NI holds monthly meetings in the area for all parents of children with ASD. This is not always appropriate for those children and young people with AS but parents are encouraged to go. This is an issue in parent support groups. The needs of those with ASD are diverse and vary with age, the severity of the condition and intellectual ability. Some areas have separate parent groups dependent on age, or recency of diagnosis, or

have different groups for those with AS and those with autism and learning disabilities.

The parents' concerns are usually school-related, including behaviour in school, bullying, limited independence skills, refusing to leave the house and limited social skills. Autism Initiatives have been very helpful with some children and young people when the family has been at the point of breakdown. Their intervention has helped to get the child out of the house or to find them a part-time job. This organisation is planning to set up 'one-stop shops' for children and young people and adults with ASD. They have already established such a service in Edinburgh.

7.1.5 Interviews with social workers who specialise or have an interest in ASD

One social worker specialised in ASD and had a caseload of children and young people aged from 3 to 24 years. She had developed her own plan of action and an assessment proforma for her work in ASD. She said that she did not want families and others to see her as being in a child protection role. What she does is to map all the other professionals involved with the child or young person, and also gives them information on the blue badge scheme, the Family Fund and the Disabled Living Allowance (DLA), together with details of summer schemes. She may also give parents ready-made letters as a template.

This social worker had made a card for each family entitled the '*Shared Priority Care Plan*' which showed that the child or young person was known officially to services. The parents are asked to complete a questionnaire on their own child, and in their own time, as they are the experts. This social worker asks the parents for their priorities. In her experience, parents often underestimate the demands on their time when completing forms for allowances and forget about limited sleep and their child's need for almost constant supervision or attention. Parents are given her office number and told that the call will always be returned although it may take a while. She is also happy to become involved with schools, if they wish.

There is not enough provision during the summer holidays for the families. Autism NI, the Red Cross, and Autism Initiatives have set up schemes, but these do not meet demand.

Another social worker interviewed said she thought that parents would say their biggest needs were:

- Anger management;
- Lack of input from therapists;
- Mental health issues.

Section 8: FINDINGS

Role and Work of the Voluntary Organisations in ASD in Northern Ireland

8.1 Introduction

There are four main voluntary organizations currently working in Northern Ireland which specialise in providing for and supporting children, young people and adults with ASD, and their families and carers. These are:

- Autism Northern Ireland (Autism NI), formerly known as PAPA (Parents and Professionals and Autism)
- Autism Initiatives
- Asperger's Network
- National Autistic Society

A summary of their work is included in this Review. Data is taken from interviews with staff within the organisations and from their literature. Further details can be obtained from their websites.

8.2 Autism NI (formerly PAPA (Parents and Professionals and Autism))

(www.autismni.org)

8.2.1 Introduction

Autism NI has been established for over 15 years in Northern Ireland and is held in high regard by many parents and professionals. It has provided funding so that professionals can train in TEACCH, the DISCO and ADOS. They hold social events and circulate newsletters. No concerns were expressed by the professionals

interviewed for this Review in terms of their work. Overall, Autism NI was seen as supportive to professionals, and very fair and very good at lobbying by the professionals interviewed for this Review.

Autism NI has over 700 members including professionals and parents. Its mission statement states that it:

'seeks to ensure that people within the autistic spectrum and their carers have access to appropriate services, enabling people with autism to be valued members of their community.'

They have 15 branches throughout the Province and have recently appointed a Development Officer to coordinate and support the work of the branches. It is not a service provider, in the sense of having its own units, schools or centres for individuals with ASD, nor does it see itself as an organization that should provide services. Rather, it exists to support the work of professionals in the statutory sector and to lobby key groups, including Governments, to enhance services. Its four main functions currently are to provide up-to-date and good quality information on ASD and materials for families, to host and convene support groups for parents and individuals with ASD, to promote and arrange training events and to lobby local and national governments.

At present Autism NI does not have a central database and the data they have are not classified by diagnosis or age. For £15 a year, parents can join the library and borrow resources. Parents are offered training, often free of charge. The Chief Executive, Arlene Cassidy, and her Deputy, Fiona McCaffrey, say they pride themselves on working with professionals and strive in all that they do to support the statutory services. Much of the work done by Autism NI focuses on training parents and professionals on how best to work with children with ASD. Autism NI has recently signed a partnership agreement with Autism Initiatives, which is on the same site as Autism NI, largely connected to a code of conduct to ensure they are working together effectively.

Autism NI is also very keen to lobby ministers on behalf of people with ASD and to link with other lobbying groups in the UK. They would ultimately like to see a Northern Ireland Autism Act which sets out the rights and entitlements of people with ASD and their families, and which protects their interests. Representatives from Autism NI have been to Westminster and joined with APPGA and PACE in London to support initiatives to improve services.

8.2.2 Provision of information on ASD by Autism NI

Autism NI has produced information on ASDs for many different audiences in a variety of forms (e.g. leaflets, booklets, web resources, videos, CDs and DVDs, newsletters), and through numerous training events for parents and professionals.

Autism NI has produced a leaflet for GPs on facts about autism and Asperger syndrome, which includes the CHAT (Checklist for Autism in Toddlers) and information on the branches of Autism NI (PAPA, undated). In addition, they produced a leaflet for those working in mental health services entitled, *Wake up to Asperger's syndrome: an issue for mental health services* (PAPA, undated). The three key clinical practice points included are:

- People with AS have a heightened risk of developing mental health problems, especially anxiety and depression, which may present unusually.
- These patients are at an increased risk of being misdiagnosed with schizophrenia, bipolar disorder and obsessive compulsive disorder.
- People with AS may have significant sensory problems, being hypo or hyper-sensitive which can cause significant distress and behavioural changes.

8.2.3 Supporting young children with ASD and their parents

After the Keyhole project, which was designed to support children with ASD aged between 2 and 4 years and their parents (McConkey et al., 2003), there followed Connecting With Autism (CWA). A Rainbow Resource kit was developed to use with parents of young children with ASD at home. This was funded partly by the Big Lottery Fund and partly by Lloyds. The Kit is a very colourful box of toys with activity

cards and the set of leaflets contained in the Jig Saw pack. Parts of this kit are now being used by many professionals who have been trained by Autism NI to use these. This kit has been piloted with 16 families and is being externally evaluated by University of Ulster, whose report is due in December 2006. It is on loan free of charge to families for an agreed period of time. The overall aim is to help families minimize the effects of autism and to promote their educational and social development in the early years.

The Rainbow Resource kit always comes to parents with a professional and it is not left in the home. Each family has five visits and so far the feedback has been excellent. A pilot study in December 2005 showed reduced parental stress and improved parental health. To date, two hundred and fifty boxes have been given out to families. Autism NI also offers Keyhole Early Years training along with the Early Years Organisation for Northern Ireland, NIPPA and Barnardos. Autism NI has also devised ACCESS workshops for parents of children and young people aged 3 to 16 years to address concerns following diagnosis and to help them understand their child.

8.2.4 Training by Autism NI

Autism NI also trains professionals in other areas, and has a Training Prospectus which sets out the training offered by Autism NI and by external providers giving details of content, length, venue and costs. There is a twelve-and-a-half-hour course on ASDs for playgroup leaders and nursery nurses, for example, which is accredited by AQA (www.aqa.org.uk). Such work is likely to increase awareness of ASD in the early years and lead to the earlier diagnosis of AS. Autism NI is also currently working on packs to support transition from primary to post-primary education and from home to pre-school. Other courses are held on TEACCH, Social Stories, behaviour analysis, diagnosis and transition. Autism NI has also been delivering awareness training with the School of Dentistry at Queens University in Belfast.

So far, Autism NI has trained 120 professionals in the use of the Rainbow Kit at the Autism NI offices or off-site. This includes SLTs, OTs, psychologists, classroom assistants, and health visitors. It is a two-day training course, on consecutive days if

possible. At the end, participants receive a Rainbow Kit to use as they deem appropriate. All families receive the Jig Saw pack of leaflets to keep.

8.2.5 Police Services in Northern Ireland (PSNI)

As mentioned in the Literature Review, some agencies are working with police forces to increase their awareness of ASD and to enhance their practice in this area. Autism NI, in partnership with the PSNI, will be piloting an ASD identity card in Northern Ireland similar to that issued in Wales in the autumn of 2006. Posters and information from Autism NI are also in every custody suite in Northern Ireland.

8.2.6 Research work and Autism NI

Since 1995, Autism NI has been involved in eight different research projects on different aspects of ASD, and in interventions in collaboration with other agencies and Universities.

8.3 Asperger's Network (www.aspergersnetwork.org.uk)

8.3.1 Introduction

Asperger's Network was set up about four years ago by a parent, Sharon Doherty, to support parents and young people with Asperger syndrome living in Northern Ireland. There are a number of groups for youngsters with AS which meet monthly or more frequently, and support groups for parents too. In addition, members may support one another at reviews, completing DLA forms and in addressing problems with the services. Several parents in this Review mentioned the Asperger's Network as being a lifeline in terms of providing information and support groups for parents and for their children. Some groups for the children met monthly and they played pool, cards and table tennis. They were not allowed to bring Gameboys. The parents often met outside the venue and talked to each other. Parents spoke of this group as having given their child '*a network of friends.*'

Some parents said that their son or daughter did not want to attend groups with other youngsters with Asperger syndrome. As with other peer-group activities, and

activities generally, it is important to establish what this decision is based on, and to consider ways of introducing the child or young person gradually to the new event to ensure that their decision is a genuine choice.

8.3.2 Advocacy role

An important part of the work of Asperger's Network is sitting on parent carers' forums within Trusts to advocate on behalf of the parents and the young person. Staff from Asperger's Network meet with Trust staff at the planning stages of services in the hope that these services will then meet the needs of the family and young person. Representatives from Asperger's Network also sit on the Independent Advocacy Service in Northern Ireland, advocating for parents and young people within education, Trusts and benefits. Young people are asked what type of groups or workshops they would like, and these are then set up by Asperger's Network. Workshops have been run on sex, relationships and drugs. Fathers also asked for workshops specifically for them and these have also been held.

8.4 Autism Initiatives (www.autisminitiatives.org)

8.4.1 Introduction

Autism Initiatives is a charity that was established in the North West of England in 1974 by a parent. Since then, it has expanded its work and now also operates in Northern Ireland, Scotland and Wales. It began its work in Northern Ireland in 2002. Autism Initiatives plays a key role in services for young people with Asperger syndrome and other autistic spectrum disorders in Northern Ireland. They have set up residential and day-care services for people with ASD and are also involved in training. A new service is being launched in November 2006, entitled '*Milestones and Targets*' which is aimed at young teenagers. In Belfast, Craigavon and Bangor, there are outreach services working in partnership with parents, schools and social services. Within the South and East Health and Social Services Trust, there is the first Floating Support Service for people with Asperger syndrome. The parents of the Belfast Autism NI branch and Autism Initiatives raised money to provide a Social Opportunities Group for the 14+ age group, where opportunities were provided for young people to meet, discuss issues and needs, and to build a social network. This

has been running for 18 months and a Drama and Movement Therapist has been supporting this project. In January 2005, an accredited module for students with Asperger syndrome, entitled '*Your life, your future*', started at the City Factory campus of the North West Institute.

8.4.2 Derry pilot project

The Derry project aimed to support young people with Asperger syndrome or high functioning autism. In February 2005, an evaluation was conducted on the project which reported on the outcomes for nine young adults aged between 16 and 27 years, and on the ways in which the service might be enhanced.

The three main aims of the project were:

- To provide an in-depth assessment of individuals with Asperger syndrome, to highlight their current difficulties and offer realistic recommendations for the future;
- To develop a 'hands-on' service for those individuals and their families;
- To assist the multi-disciplinary team with advice, professional guidance and aid the care and support management of those individuals with AS.

The service adopts a person-centred approach. Autism Initiatives acknowledges that people with an ASD have a continuum of need which requires a continuum of provision that responds to changing needs.

8.4.2.1 Lessons learned from the Derry pilot project

There have been five key issues in running this service, as follows:

- The adults varied in terms of the type and amount of support needed, some requiring relatively little, perhaps just being made aware of what existed, and others needing more intervention from the outreach worker;

- Some of the young men were reluctant to engage in leisure pursuits with female staff. They appeared to be embarrassed and were not keen to show their problems in social interaction to a female worker. Money allocated for clerical support was therefore used instead to appoint a male befriender to support the female worker;
- A number of adults with AS were found to be attending the same college and so a social skills group was formed within the college timetable for a six-week period. This is based on an assessment of the needs of the individuals and focuses firstly on the needs arising from AS and then provides information about Further Education, employment, sexuality, benefits and housing;
- Some adults may have significant mental health problems which make it hard for them to engage in the services offered. For outreach to work, it is essential that the young person can engage in planning, developing and monitoring the service;
- Local GPs were very willing to make referrals to this outreach service. Four of the ten referrals were from GPs, and two other referrals from GPs were possibly going to be made.

8.4.2.2 Referral criteria for the Derry project

There was an increase in the numbers of referrals to the service as the project became known. It was therefore necessary to consider more carefully the referral criteria and selection process. The key criteria determined were as follows:

- 1 An autism-specific diagnosis OR
- 2 Adults waiting for an autism-specific diagnosis OR
- 3 A diagnosis of autism and a learning disability OR
- 4 A diagnosis of Asperger syndrome OR
- 5 A diagnosis of autism/Asperger syndrome and a mental health disorder
OR
- 6 Adults not yet diagnosed, but who may have autism or Asperger syndrome

As there is not yet a social worker in the area who specializes in ASD, Autism Initiatives plans to continue to take referrals from GPs.

8.4.2.3 Details of the clients and support offered

Employment

Only four of the nine adults were eligible for employment as the rest were still in education. None of these four were able to remain in employment without support. Two adults had used the Training and Employment Agency in their search for work.

Education

Three adults were following the 'Your life, your future,' module at the North West Institute, along with another adult with AS who was not known to Autism Initiatives.

Social skills

Five adults received support with social skills from the outreach worker or the male befriender. Two of these adults would only work with a male support worker. One adult required further assessment before leisure support could be offered due to his challenging behaviour. Only one adult needed help with daily living skills, which reflects the fact that the adults in the project were cognitively able, although this does not always translate to a high level of independence skills in terms of shopping, using public transport and personal care.

Counselling

Five adults received counselling from the outreach worker. Any concerns were passed on to other agencies, with the consent of the adult.

Advocacy

Autism Initiatives acts as an advocate for five of the adults, giving advice and support on education, employment, benefits and housing.

8.4.3 Floating Support Service in South and East Belfast

This new service started in January 2006 and aims to provide a service for adults with Asperger syndrome aged between 16 and 25 years. This is being funded by the Northern Ireland Housing Executive through the Supporting People programme. The service aims to enable people with AS to live in the community, to make the transition to independent living and to maintain their own tenancy in the community. Support for an individual can be provided for up to 2 years and can range from 1 to 15 hours per week. Autism Initiatives will provide:

- Counselling and support on day-to-day issues;
- Training to keep their home in good condition;
- Support on how to access other agencies;
- Advice on budgeting and benefits;
- Support in maintaining positive relationships with others;
- Information on Asperger syndrome;
- Assistance with moving;
- Assistance with unforeseen problems.

8.4.4 Milestones and Targets project

A number of targets and milestones have been set by Autism Initiatives over the past few months to meet the needs of young people with an ASD, including, but not specifically, individuals with Asperger syndrome. Amongst their targets are the setting up of a register of young people with an ASD; the recruitment of volunteers from Health and Social Services, Training and Employment, Education and Leisure; the expansion of the 'One Stop Shop' services in Northern Ireland; the provision of

advocacy services; the establishment of friendship groups and the organisation of weekends away.

8.4.5 Future plans of Autism Initiatives 2007-2008

Autism Initiatives plans to provide a central point of contact for people with ASD. It will aim to work out of a central base, but to establish contacts points in other areas throughout the Western Health and Social Services Board, using local Autism NI groups, social services and GP practices.

8.4.5.1 Aims of the service

- To provide relevant support pre- and post-diagnosis for adults with ASD, their families, carers and professionals, including counselling;
- To provide support to access Further Education, training, and employment and to maintain these placements;
- To provide support to access health resources and health-related education;
- To assess, plan and evaluate;
- To provide practical outreach support in daily living, leisure and social skills;
- To provide Benefit advice and relevant advocacy;
- To assist with supported housing initiatives throughout the WHSSB area;
- To work with relevant agencies to provide relevant training for service users, professionals and carers;
- To provide a full range of services for people with ASD.

8.4.5.2 Service Team and availability

A core staff team will be recruited, consisting of a Project Manager, two outreach support workers and administrative staff. The service will be accessible from 9am to 5pm, Monday to Friday. Request by phone or visits to the service will be dealt with promptly. The Project Manager, together with the outreach workers, will use the autism-specific tool '*What I want*' (WIN) devised by Autism Initiatives.

8.4.5.3 Types of service likely to be provided

Training, educational and employment opportunities will be explored and supported. The Project Manger will be responsible for the establishment of links with employers and the arrangement of suitable work placements in conjunction with the Disabled Employment Adviser (Training and Employment Agency). Training will be offered to service users, parents, carers, professionals and other agencies. This will be free for service users and parents.

8.4.5.4 Evaluation of the service

The service will be evaluated on a continual basis to ensure the development of long-term provision, value for money and best practice, or to decide on the revision of the strategy and service. The Project Manager will develop performance indicators against which the service can be measured.

8.5 National Autistic Society (NAS) (www.nas.org.uk)

8.5.1 Introduction

NAS has four offices in Northern Ireland. It has set up social groups for children and young people with AS aged 16 and above in four different areas, and offers support to about 60 children and young people with AS. The Belfast group is well established and has about 25 children and young people on roll, with between 10 and 12 young people attending at any one time. They meet at a variety of venues depending on the wishes of the group. NAS also offers a befriending service to families sponsored by Vodaphone. Training is given to the volunteers, and these activities are publicised in GP surgeries, clinics and by word-of-mouth. There are plans also to offer the HELP programme which is a parent training programme, for parents of older children with ASD.

SECTION 9: CONCLUSIONS AND RECOMMENDATIONS

9.1 Introduction

This Review took place over a six-month period and so there was not the time or resources to make a detailed and comprehensive study of the services provided for children and young people with Asperger syndrome by Education, Health, Social Services and the voluntary sector throughout Northern Ireland. However, it is very likely that the responses by the thirty-five children and young people with AS, the fifty-nine parents and carers, the 205 schools and colleges, and the individual and group interviews with professionals working in Health, Social Services and the voluntary sector highlighted the main issues and concerns, and identified developing practice and projects in relation to this group of young people. Overall, there was evidence of improvements in services in the last few years and a real willingness on the part of professionals to enhance services.

Children and young people with AS and their parents/carers will meet many people in their school lives, work and leisure, some of whom will not have knowledge of AS. It is therefore inevitable that issues will arise and that parents and young people with AS will feel frustrated and let down. It is hoped that with the work being done in all the statutory services, sometimes initiated by and supported by the voluntary sector, such eventualities will decrease with time. There is no room for complacency in services in Northern Ireland or in the rest of the UK in relation to this group, nor should parents or professionals feel downcast. Many very useful resources and services have been produced and developed within Northern Ireland and other parts of the UK. There is a clear willingness amongst professionals in Health, Social Services and Education to enhance provision in relation to this group, and Autism NI, Autism Initiatives and the work of Asperger's Network do much to supplement and support this work. The Literature Review shows that there is now a much better understanding of Asperger syndrome and its implications, and of how best to support children and young people with this diagnosis. Areas for further study are suggested by the findings and recommendations, and can be discussed and explored in order to develop and enhance provision for the benefit of all.

The next sections draw together the main findings of the Review and the final section makes a series of recommendations which readers might consider in relation to their own situation – whether as a person with AS, a parent or carer, a professional working in Health, Education or Social Services or within the voluntary sector.

9. 2 Key points to bear in mind when reading this report

Those with Asperger syndrome have diverse needs so it is not possible to prescribe what should happen for ALL children and young people with this diagnosis. There will need to be a range of services and types of support with different options for families and young people with AS. That said, there are some areas in which almost ALL those with AS will have needs. These are the areas of communication (both their own communication and their understanding of others' communication); their social understanding and social inclusion with peers; their flexibility in thinking and behaving; their problem-solving skills and ability to ask for help; their methods of relaxation; management of anxiety and anger; and their daily living skills (including crossing the road, using public transport, shopping).

9.2.1. Needs in common

Responses from the children and young people, and their parents and teaching staff identified a number of areas in common where difficulties arose and where support was needed. It is recommended that as a matter of course, these areas are assessed in relation to EVERY child or young person with Asperger syndrome, as it is extremely likely that they will need support or advice. In fact, it might be useful if those engaged with the child or young person had to consider each one of these questions at every review, that is, to take the view that the child or young person with AS is very likely to have needs in these areas and if the view is that s/he does not, then evidence needs to be provided to this effect. So at a minimum, a child or young person with Asperger syndrome should be assessed and supported in relation to the following areas (given here in alphabetical order):

- Bullying and teasing, protection from
- Daily living skills
- Employment advice and support once in work

- Exams
- Further Education
- Friendships in and out of school
- Higher Education
- Homework
- Independent living
- Transition to a new class each year
- Transition to a new school/college
- Work experience
- Writing: physical issues, creative writing and writing accounts

Some children and young people 'pretend' to be normal, but this is very effortful and they need time to 'be themselves'. High intellectual ability or high levels of skill in some areas, does not mean that they have high levels of skill in other areas. Their abilities may mask their difficulties. Good spoken language, for example, may hide their problems in processing and understanding. In terms of self-care and independence skills (e.g. washing, dressing, shopping, crossing the road, cooking), these are often problematic as they involve rapid information processing, flexible thinking, and social understanding.

9.3 Awareness and information on Asperger syndrome in Northern Ireland

This Review found that much work has been done recently in Northern Ireland to increase awareness and expertise in AS in a number of ways, and so parents in the future should be better informed and supported. The five ELB ASD Advisory teams have each produced their own packs for parents containing leaflets on local services, useful strategies, checklists to complete on the child to identify strengths and needs (e.g. from Cumine et al., 2000), websites, and articles on AS (e.g. Attwood, 2002 on friendships), and on how to look after themselves as parents. In addition, Autism NI has created Rainbow Resource Kits for use by parents of young children with ASD in the early years.

9.4 Number of children and young people with AS living in Northern Ireland

Even if this study had been done over a longer time frame with more resources, gaining an accurate figure of the number of children and young people with AS is a very difficult exercise for the reasons outlined in the Literature Review, namely there is no definitive method for confirming diagnosis, and databases are kept by different agencies but often not shared. It was possible, however, to analyse the data kept on the number of pupils with AS by the Department of Education in Northern Ireland. This Department has created an excellent database following recommendations made in the report on AS by the Education and Training Inspectorate (ETI) in 2001. These data cannot be wholly accurate and reliable for reasons which have been outlined, but the figures do provide a very good basis for planning and studying trends.

9.4.1 Number of children and young people with AS and autism in Northern Ireland

Current figures for Northern Ireland indicate that there are just over 1,000 school-aged children and young people diagnosed with AS and 1,332 school-aged children and young people with autism, as listed on the SEN register and reported by schools (only).

9.4.2 Regional differences in identification of Asperger syndrome in schools

Overall, and when child population figures are taken into account, schools in the South Eastern Education and Library Board have identified the greatest number of children with AS, at a rate of 43 per 10,000 and schools in the North Eastern Education and Library Board has identified the lowest number of children with this condition. A detailed study of individual case histories and diagnostic practice would need to be made to examine the possible reasons for the differences between the identification rates for each Education and Library Board. It is likely that there are several factors involved, including expertise of professionals, awareness of AS in schools and by parents, and ability to access and provide services.

9.4.3 Ratio of autism to Asperger syndrome and gender

In terms of the ratio of autism to AS, there are many more pupils identified as having Asperger syndrome (as compared to autism) by a ratio of 3.5 to 1. All the Boards have identified more pupils with AS than with autism. This is in line with epidemiological studies which suggest a rate of 22/10,000 for autism and 36/10,000 for Asperger syndrome (MRC, 2001).

For nursery-aged children, as one might predict, there were more children diagnosed with autism than Asperger syndrome, as the latter is often not picked up until the primary years or later. In the primary schools, the totals for autism and AS were fairly similar, although in the secondary schools, there were many more children with AS than autism.

For the post-primary data, the gender of the pupils is also given which is interesting to examine. Epidemiological studies show that there are many more males than females with autism (4:1) and Asperger syndrome (maybe 10:1) (MRC, 2001). This is reflected in the data for Northern Ireland. For the autism group, the ratio is 8:1 and for the AS group, the ratio is 6.5 to 1. In terms of category of ASD, these ratios are the reverse of what the literature suggests, as the number of females is generally lower in the Asperger group. More detailed analysis of the diagnoses given to individual children, and the data on which schools are basing these judgements would need to be made to explore the possible reasons for this.

9.5 Type of school placement

Given that one of the diagnostic criteria for AS is that the child or young person has average or above-average intellectual ability, one would predict that most of these pupils will be placed in mainstream schools. However, data from special schools, show that there was a total of 66 children and young people attending special schools and three of the parents who completed questionnaires had children in this sector. It may be that some of these children did have intellectual impairments and so were wrongly identified as having AS. But it is likely that some of these children did have AS and were of average or above average intelligence. For some children with AS, their local mainstream school may not be appropriate, and the smaller class

sizes, knowledge of specific strategies and a smaller physical site and lay-out are advantages which special schools can offer to enable such pupils to be more relaxed and be educated more effectively.

9.6 Practice in schools now as compared to 1999

Seven years on from a survey by the Education and Training Inspectorate on provision in mainstream primary and secondary schools for pupils with AS during 1999-2000 (ETI, 2001), the responses from schools in this Review suggest there has been some movement and improvements in some of the areas which required attention, namely, that more teachers have in-depth knowledge and appropriate skills to plan for the specific needs of pupils with AS, that staff are more likely to involve parents, and that the advisory services have been expanded and produced ASD-specific materials. Some teachers in this Review commented on the need to involve parents, and had increased the time they spent in discussion with parents. Support from the advisory staff was welcomed and seen by some as meeting the needs of the children and young people.

For some schools and children and young people with AS, where staff are new to the condition, there is still insufficient knowledge and support for children and families. Problems still remain in the areas of long-term planning, and delayed decisions about future placements. Advisory services are often stretched so that mainstream teachers have less support than they would wish. Parents in the Review commented on the intermittency of support and the lack of planning and preparation for their child when moving on to schools or adult placements. It was left to parents in some cases to take the initiative, and to prepare and support their child on their own.

9.7 The perspective of the children and young people with AS

Data from the 35 children and young people in the Review showed that some had positive expectations and views of themselves, but many were also well aware of the difficulties they had, particularly in understanding other people and making friends, and they were often very conscious of the negative responses of other people towards them.

Most of the statements they made about AS showed very good insight and understanding into how Asperger syndrome was defined, with none of the 35 children making a statement that was erroneous or mythical. This reflects well on the discussions that parents and others have had with the children and young people, as work with other groups of children and young people with AS has sometimes highlighted information about AS which was incorrect (Jones, 2002). Teasing and bullying was most frequently mentioned by children and young people as a problem at school and outside, and also by parents. Yet this was not often mentioned by school staff. This discrepancy is true for schools in other parts of the UK. Parents often report bullying to school staff, but this is not recognised by staff and played down. This issue needs further study to explore what can be done to protect children and young people with AS, and to help them to report incidents.

9.7.1 Views about school/college by children and young people with AS

Overall, children and young people made more positive ratings about school/college than 'dissatisfied' ratings, which is encouraging, although some aspects were rated 'not at all satisfied' by almost a third of young people (i.e. homework and test results).

Twenty-three (68%) of the young people said they would have liked their school or college to be different. Many had good, practical suggestions to make, which points up the value in asking children and young people directly. Heather Moran, a clinical psychologist in Coventry, has developed a very creative way of gaining this information from children with ASD (Moran, 2006).

9.8 Views of the parents and carers

9.8.1 Age of the child at diagnosis and satisfaction with diagnosis

Sixty per cent of the children were not diagnosed until late primary age (i.e. between 9 and 11 years) or secondary age. Fourteen children (24%) were not diagnosed until they were of secondary school age. Professionals in Northern Ireland recognise that more resources are required to reduce waiting lists and to increase expertise and awareness of AS and ASDs in order to bring down the age at diagnosis. From discussions with the SIG group on diagnosis, it was clear that there was a real

willingness to improve multi-disciplinary working. About 40% of the parents were either 'very' or 'quite satisfied' with the diagnostic process, but more than half were not.

9.8.2 Additional diagnoses

Over half of the parents (56%) of children and young people with AS said that their child had another diagnosis in addition to Asperger syndrome, 24 having one additional condition. Some of these conditions are known to have an association with autism, such as epilepsy, but others did not (e.g. diabetes, heart condition).

9.8.3 Satisfaction with current school/college

Over half of the parents were satisfied with the child's current school or college placements and said this was their greatest source of support. Some of these parents, though, had had great problems with schools in the past and had taken their child out of the school. A quarter of the parents were not satisfied with how the school or college addressed their child's needs.

9.8.4 Classroom assistants

The allocation of classroom support is often seen by parents as an essential resource to ensure that there is someone both '*looking out for their child*' and acting as translator and mediator for academic tasks. It is very hard for ELBs to estimate how many hours a pupil should be allocated. There are issues about children and young people with AS either becoming over-dependent on the CA or not wanting to be singled out as different. In addition, some parents were not happy if the assistant was changed or asked to work elsewhere in the school, so they were not available for their child. It is desirable for all adults who meet the child to develop skills and understanding so that the child learns to work with a range of people and is not bereft if his or her key person leaves the school or college.

9.8.5 Overall level of satisfaction by parents/carers

Parents were asked to rate on a scale from 1 to 10, how satisfied they '*felt today about the level of help and support*' they were receiving (with 1 being very dissatisfied and 10 very satisfied). Twenty-three parents (41%) who gave a rating

were very dissatisfied with the support they were currently receiving and only six (11%) gave a rating of 10 showing they were 'very satisfied', two of these parents citing Asperger's Network as their main support and a third parent citing a private psychologist. There are potentially many areas of life where the child or the parents/carers need support and so these ratings are perhaps not surprising. In most parts of the UK, including Northern Ireland, it is important to consider how families might be supported out of school/college hours, in the evenings and weekends, and to address the needs of siblings and other relatives.

9.9 Responses from school and college staff

Overall, the tone of their replies was very positive and almost ALL schools and colleges which had students with AS could point to improvements over the last 3 years, both in terms of what they were able to do and in their understanding of the condition. This appeared to be the case across the five Education and Library Boards.

9.9.1 Training issues

Several respondents referred to the fact that they had learned and developed their expertise by working with the student in the school. Many had also appreciated the input from the ASD Advisory teams.

9.9.2 Extent to which the needs of those with Asperger syndrome were met

Many replies from school and college staff were very positive in that they showed a real willingness to want to know more and to change practice to better meet the needs of the students with AS, and this was very heartening. Eighty-one per cent felt they met the children's needs 'very well' or 'quite well'. Fifty-one (60%) of the eighty-five respondents from schools with students with AS or HFA on roll, said ALL staff felt the placement was appropriate, thirty (35%) felt that only SOME of the staff thought it was appropriate and only two respondents said that NONE of the staff felt it was appropriate, believing instead that a special school placement would be easier for the student.

9.9.3 Consultation with children and young people with Asperger syndrome

Twenty-five respondents (29%) felt that they consulted pupils with AS very well, 39 felt they consulted on some issues. Seventeen respondents (20%) felt they did not consult very much, and two said they did not consult at all with students with AS. Given that pupils with AS are intellectually-able and have good language skills, it is surprising that a relatively high proportion of staff report that they do not consult with them very much. It is the case that many with AS would find making decisions and giving feedback on their experiences difficult, but this makes consultation all the more important, so they can practise these important life skills.

9.9.4 How could the students with AS be better supported in school/college?

The majority of respondents from schools had suggestions on how students might be better supported. Twenty-three (53%) referred to more awareness training for staff; six (14%) wanted more advice on specific strategies; and five respondents wanted either more CAs, more advisory time or a specific resource. Resources mentioned included a safe haven, a sensory room, and ICT. Other ideas mentioned included advice on students with AS who were bilingual, more out-of-school activities and improved provision post-16.

9.10 Issues raised by professionals in health and social services

The key areas identified by professionals working in health and social services were:

- The need to increase awareness and expertise in AS;
- The need to train staff in the use of diagnostic instruments and procedures;
- The need to reduce the waiting lists for diagnostic assessment following referral;
- The need for more resources to support families following diagnosis;
- The need to create efficient and effective databases which were shared across agencies;

- The need to allocate a key worker for some families;
- The need to extend services for children and young people with AS with a mental health disorder.

9.11 Training issues in Asperger syndrome

In Northern Ireland, as in many other areas in the UK, there are many forms of training in ASD, including Asperger syndrome, in terms of delivery, provider, content and whether the training is accredited. It would be useful to conduct an audit of the training available in each area, and to map this in terms of content and level and keep a register of who is trained. When a school or Board or area is offering funding for training, there is a need to consider how best this money can be used.

In the West Midlands region of England, a working group has been meeting for two years to consider the different types of training offered and the different content needed, depending on the target audience and previous training and experience. A document has been produced on the basis of these discussions entitled a '*Training Framework in ASD*' (FREDA & Jones, 2006). This suggests that training is needed and currently delivered by a range of providers to different audiences and at different levels. The four levels have been defined as awareness, foundation, core and extension. These do not relate to the entry qualifications of the participant, but to their prior knowledge of ASDs so, for example, a support assistant might be studying at the core or extension levels, whereas a GP or psychologist might be studying at the awareness or foundation level. For each level, there are a number of topics listed, together with the knowledge and skills intended to be taught. The framework is intended for use in planning training and in auditing the training that an individual has received. Providers can be guided as to what to cover, and Services can be assisted in knowing what a trained person will have covered. It aims to create more consistency in what is delivered. Clearly, the topics will change as understanding grows, and the priorities given to each topic will be debated, but it is a first attempt to enable those in the region to consider what is being offered and received.

A major question that was posed and discussed during the development of this Training Framework is how we might assess the impact of training on a person's practice. Often training is done off-site, or by an external trainer within a school or centre. There is then little opportunity to ascertain what the practice is like before and after the training. For external trainers, it would add to the costs of the training if they were to visit schools and centres before, during or after the training. But for those who are delivering training themselves in school, for example, methods of gauging effects of the training should be considered. Some courses require students to keep a portfolio of work based on practice, or to write an essay which asks for reflection on their practice and developing knowledge. A course in the Republic of Ireland asks students to select a task or piece of work for children with ASD to implement in their classroom or school and the course tutors then visit the school to see this in action. Asking students to bring in video records or other materials which demonstrate practice are also very useful.

9.12 The role and work of the voluntary sector

The four main voluntary organisations with a specific remit for ASD within Northern Ireland are:

- Autism Northern Ireland (Autism NI), formerly known as PAPA (Parents and Professionals and Autism)
- Autism Initiatives
- Asperger's Network
- National Autistic Society

They appear to work effectively with the statutory services and complement the work done with parents and carers and with children and young people themselves.

Autism NI, in particular, has a key role in providing training and resources for professionals, as well as for parents. It is also a powerful lobbying agent for change and is working to have legislation passed to protect the rights of those with ASD and to advocate specific teams for ASD to be set up in statutory services. Asperger's Network runs groups and activities for children and young people, and will advocate on behalf of parents and young people. Autism Initiatives sets up and runs services

to support young people with AS in housing, employment, leisure pursuits and transition to independent living. NAS is involved in running parents groups, and offers parent training after diagnosis in the form of the EarlyBird and HELP programmes.

9.13 Key recommendations arising from the Review

Recommendation 1:

It would be very helpful to create just one database within a geographical area to which all agencies in Health, Education and Social Services contribute and access. There are some serious ethical and logistical issues to resolve here, so as yet, it remains a desirable but distant goal. The Department of Education has a single database for all children with Asperger syndrome with SEN in the schools sector which is available by geographical area and Board area.

Recommendation 2:

For Education, Health and Social Care to consider how the caseloads of those with posts with specific responsibility for ASD are best managed and their resources used effectively to meet needs. The Department of Education is currently carrying out a review of SEN and Inclusion, which will consider the management and use of Board resources.

Recommendation 3:

For those in Education, Health, Social Care and the voluntary sector who have a brief for training, to audit the training available, received and required in their area. The Department of Education review of SEN and Inclusion is to consider future models for Board training.

Recommendation 4:

For each ELB and HSSB to consider their current practice concerning diagnostic assessment in relation to the guidance produced by the four Health and Social Services Boards in Northern Ireland (Four Board paper, 2003), the National Autism Plan for Children (NIASA, 2003) in England and SIGN in Scotland (SIGN, 2006), and to determine how waiting times might be reduced, good information provided to

parents and follow-up consultations arranged so that all families, wherever they live, have a consistent and good quality service.

Recommendation 5:

For statutory and voluntary agencies to create mechanisms to evaluate the accessibility and take-up of services by families, to ensure those that require services receive these and that resources are allocated effectively and fairly.

Recommendation 6:

For social services to work together with the voluntary sector and Education to establish more provision and schemes to support parents and families in activities out of school hours, during evenings, weekends and holiday periods.

Recommendation 7:

That professionals and the voluntary sector consider how they might address some of the other needs that parents have in relation to themselves and other family members.

Recommendation 8:

For all those involved with a child or young person with Asperger syndrome and the family to consider the roles and knowledge of others, and to endeavour to present a coherent and streamlined programme of assessment and intervention to the family.

Recommendation 9:

For those working in Education, Social Care, Health and the voluntary sector to consider ways of informing other professionals and members of the public about Asperger syndrome so that others can understand their perspective and behaviours.

Recommendation 10:

That the variation in diagnostic rates between the five ELBs is explored and diagnostic practice is standardized, as far as possible, following published guidance (e.g. NIASA, 2003; SIGN, 2006) in order to ensure that resources are allocated appropriately and fairly by the Department of Education and the Health and Social Services Boards.

Recommendation 11:

That the five ELBs consider how the post-primary schools will manage and meet the needs of the increasing number of pupils with Asperger syndrome in the future, referred to as the 'autism wave' in the Task Group Report on Autism in 2002, in terms of resources and training.

Recommendation 12:

For those in all the statutory services and the voluntary sector to consider the resources and training available to professionals and parents, and evaluate how these are best delivered. As a matter of course, the Education and Training Inspectorate (ETI) reviews the use of ASD materials produced by the Department of Education during school inspections.

Recommendation 13:

Those in the voluntary sector and the statutory services need to continue to work together and liaise to ensure that what they offer is congruent and avoids repetition and confusion for families. Each needs to decide in which areas they are best qualified, and be willing to address and share their development plans and goals, be they in training, resources on ASD or support groups, for example. Two of their most valued 'products' by parents are the support groups, and the befriending schemes for themselves and for their children, and these could be expanded to increase in frequency and to reach more families.

Recommendation 14:

Parents and schools need guidance on how best to assess the needs of children and young people with Asperger syndrome and then to make sensible decisions on which interventions (in the broadest sense of the term) to use. Understanding the principles of the interventions is the key, rather than using interventions without sufficient training. This is compatible with the policy of the Department of Education — the approach should be child-centred and not method-centred.

Recommendation 15:

A key question for all providers to ask parents is ‘What would make a difference to you and the family at this point?’, as opposed to only offering what exists within an area (e.g. ‘We have a group/a workshop/a befriender/.....’).

Recommendation 16:

That young people with AS are given much more support than they appear to receive currently in choosing a suitable route after school, in obtaining support in Further and Higher Education and in finding and keeping employment At the moment in the UK, this often falls to the voluntary sector, but those working in schools, and in FE and HE should examine their policy practice in this area and work with statutory agencies to enhance current provision.

Recommendation 17:

That professionals are mindful of the dilemmas and issues in giving the diagnosis of Asperger syndrome to a child or young person, and in deciding whether to disclose this to peers, teaching staff and to future employers. There is a need to enable parents and the child or young person to arrive at the most appropriate course of action at any given time.

Recommendation 18:

All those involved with a child or young person with Asperger syndrome need to identify that individual’s skills and strengths, and find ways of recording and highlighting these to raise their self-esteem and status in the eyes of others.

Recommendation 19:

That staff in schools and colleges are made very aware of the high probability of bullying and teasing, and that they identify crisis times within the school day and areas of the school where this is most likely to occur.

Recommendation 20:

It is only relatively recently that attention has turned to sharing the diagnosis and discussing this with the individual with Asperger syndrome (Murray, 2006). Many adults have written about the huge benefits they have had from meeting others with

AS. Both these interventions need careful consideration as they are not automatically perceived by the young person as a good or positive thing. What is important is that the two topics are on the agenda for discussion with parents, professionals and the young person him or herself so that the child or young person does not lose out.

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Schools

Birmingham LEA has produced 2 DVDs on inclusion in mainstream primary and secondary schools. These can be purchased for £19.99 and £35 respectively from: Jane_jones@birmingham.gov.uk

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Useful Journals

Good Autism Practice Journal

This journal is published by BILD and contains articles on good practice in ASDs in relation to both children and adults. Articles are written by parents, by professionals in Health, Education and Social Services and by individuals with an ASD themselves. For subscription details, you can write to Pam Mazurek, BILD, Campion House, Green Street, Kidderminster, DY10 1JL or email her at: p.mazurek@bild.org.uk

Autism: The International Journal of Research and Practice, published by Sage

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Useful Websites

Autism Initiatives

www.autisminitiatives.org

Autism Northern Ireland (ANI or PAPA)

www.autismni.org

Asperger's Network

www.aspergersnetwork.org.uk

PEAT

www.peatni.org

Education and Library Boards

www.selb.org

<http://www.education-support.org.uk/parents/special-education>

(five Education and Library Boards support website)

Irish Society for Autism

www.iol.ie/~ias1/

National Autistic Society, England

www.autism.org.

Autism Cymru (Wales)

www.awares.org

The Scottish Society for Autism

www.autism-in-scotland.org.uk

Asperger syndrome

ASPIRE (Asperger Syndrome Association of Ireland)

www.Aspire-irl.com

Post-16 provision

www.skill.org.uk

Set up by those with Asperger syndrome/autism

www.isn.net/-iypsy

www.asperger's syndrome.com

www.mugsy.org/wendy

Resources, information and conference presentations

www.autismconnect.org

www.autism-resources.com

www.info.autism.org.uk

www.tonyattwood.com/

www.TheGrayCentre.org

www.udel.edu/bkirby/asperger/ (an American site with information and strategies)

Resource for primary care

www.nes.scot.nhs.uk/asd

www.sign.ac.uk

Information on benefits and Disability Living Allowance

www.dwp.gov.uk/lifeevent/discare