

Try Living in Our World



**Young People with Asperger Syndrome:
A Review of Needs and Services**

UNIVERSITY OF
BIRMINGHAM

Summary Report - March 2007

NICCY
northern ireland commissioner
for children and young people



AUTHORS

Dr. Glenys Jones
Dr. Jean Ellins
Karen Guldberg
Professor Rita Jordan
Andrea MacLeod
Lynn Plimley

COMMISSIONED BY

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

NOTE TO READER

The full version of this summary report is available to download on the NICCY website (www.niccy.org).

A list of further reading and useful contacts, compiled by the authors of the report, is also downloadable from the NICCY website.

ACKNOWLEDGEMENTS

NICCY and the Autism Team at the University of Birmingham wish to thank all those individuals and organisations whose contribution or participation made this review possible. Particular thanks are due to:

- The Review Steering Group, for their guidance and willingness to share their expertise;
- The two young people who acted as consultants to the Review;
- The parents, professionals and young people within:
 - Aspergers Network;
 - Autism NI;
 - Autism Initiatives;
 - Department of Education;
 - Education and Library Boards;
 - Health and Social Services Boards;
 - Employment for Autism;
 - Special Interest Group; and
 - Independent Psychology Services;
- The staff in the schools and colleges who completed questionnaires; and
- The parents/carers and young people with Asperger syndrome, for completing questionnaires and sharing their views with the Review Team.



CONTENTS

1. Introduction to the Review

- 1.1 The Role of NICCY
- 1.2 Asperger Syndrome: A Definition
- 1.3 The Prevalence of Asperger Syndrome within NI
- 1.4 Commissioning of the Review
- 1.5 Aims and Objectives of the Review
- 1.6 Methodology
- 1.7 Participants in the Review

2. Findings of the Review: Young People's Perspectives

- 2.1 Living with Asperger Syndrome
- 2.2 Experiences of School/College
- 2.3 Support for Young People with AS

3. Findings from the Review: Parents/Carers' Perspectives

- 3.1 Diagnosis
- 3.2 Support Post Diagnosis
- 3.3 Schooling
- 3.4 Parental Concerns
- 3.5 Support for Parents and Other Family Members

4. Findings from the Review: Professionals' Perspectives

- 4.1 Schools' Perspectives
- 4.2 Other Professionals' Perspectives

5. Key Findings and Conclusions

- 5.1 Prevalence of Asperger Syndrome within NI
- 5.2 Diagnostic Issues
- 5.3 Supporting Children and Young People with AS
- 5.4 Supporting Parents/Carers of Children with AS
- 5.5 Statutory Responses to AS
- 5.6 Recommendations



1. Introduction to the Review

1.1 The Role of NICCY

The Office of the Northern Ireland Commissioner for Children and Young People (NICCY) was established in November 2003 in accordance with the provisions of 'The Commissioner for Children and Young People (Northern Ireland) Order' 2003.

The principal aim of the Commissioner is to 'safeguard and promote the rights and best interests of children and young persons' within Northern Ireland. The Commissioner is further tasked to keep under review the adequacy and effectiveness of 'law and practice relating to the rights of children and young persons' and, specifically, those 'services provided for children and young persons by relevant authorities'. All this is done with explicit reference to the United Nations Convention on the Rights of the Child, as ratified by the UK government in 1991.

1.2 Asperger Syndrome: A Definition

Asperger syndrome (AS) is a subgroup which falls under the umbrella term of Autism Spectrum Disorder (ASD).

All individuals with an ASD (AS or otherwise) share a common core of difficulties ('triad of impairments') that define their condition and differentiate it from other conditions. Jordan (1999) identifies these difficulties as relating to (a) social and emotional understanding; (b) all aspects of communication; and (c) flexibility in thinking and behaviour.

Whilst this triad of impairments is common to all individuals with an ASD, individuals with AS are generally more intellectually and linguistically able than those in other categories. This ability has, on occasion, resulted in AS being described as 'a mild form of autism', but this description is potentially misleading as it is not necessarily the case that the nature and impact of the difficulties associated with AS are mild.

1.3 The Prevalence of Asperger Syndrome within NI

It is not possible, given current diagnostic and recording practices, to establish the exact numbers of children and young people with AS within Northern Ireland. Estimates/indications can however be made on the basis of available data.

Department of Education (DE) statistics reveal a total of 1019 children and young people with AS attending

schools (nursery, primary, post primary and special) within NI in 2005/06. This equates to a prevalence rate of 30/10,000 within the pupil population, slightly below the expected rate of 36/10,000 found in prevalence studies.

1.4 Commissioning of the Review

It was only in 1981 that Asperger syndrome was recognised as a distinct syndrome by Lorna Wing. Since that time, professionals throughout the UK (in health, education, social care and the voluntary sector) have been working hard to develop systems and methods to identify those with AS and create effective interventions and supports where required.

Knowledge and understanding of AS has developed significantly in the last 5 years, as has the provision of services within the field. There are, however, aspects of service provision that are not yet adequately developed and, as a result, children and young people whose needs are not yet adequately addressed.

The needs of these children and young people have been brought to the attention of NICCY from a number of different sources in recent years. Their experiences also fall directly within a number of NICCY's priority areas, namely those of children and young people with disabilities; special educational needs; and more generally, the effective implementation of children's rights.

NICCY commissioned this "Northern Ireland Based Review of Needs and Services for 10-18 Year Olds who Have Been, or Are Currently in the Process of Being, Diagnosed with Asperger syndrome" early in 2006. The Autism Team at the University of Birmingham secured the contract for this review and commenced work in January 2006.

1.5 Aims and Objectives of the Review

The overarching aims of the Review were:

- To identify the needs of young people with AS 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.



The specific objectives of the Review were:

- The production of a comprehensive literature review;
- The production of a comprehensive overview of existing services and provision for individuals with AS within NI;
- To identify examples of good practice and gaps in service provision within NI;
- To ascertain the views of children and young people, their parents/carers and relevant professionals regarding (a) the diagnostic process; (b) the effectiveness and appropriateness of existing services; (c) the extent and nature of unmet need; and (d) desired developments within the field; and
- To offer evidence-based recommendations for the future development of both policy and practice.

1.6 Methodology

The Review was carried out between January and October 2006 and comprised the following strands of investigation:

- A review of current literature and research relating to AS and ASD;
- A review of relevant policy, legislation and guidance within NI;
- The collation and analysis of existing statistical data;
- The design and circulation of questionnaires to children and young people with AS, their parents/carers, schools/colleges and other providers of services; and
- Face-to-face or telephone interviews with children and young people with AS, their parents/carers, health professionals and social workers.

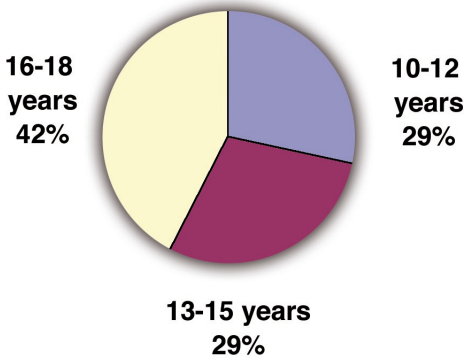
1.7 Participants in the Review

A total of 35 children and young people with AS, aged 10 to 18 years inclusive, participated in the Review via completion of a youth friendly questionnaire (see Figure 1). Ten of these young people also completed a face-to-face interview with a member of the Review team.

A total of 59 parents, from across all 5 Education and Library Board Areas, also completed and returned written questionnaires.¹ Twenty of these parents completed a face-to-face or telephone based interview as well, as did 42 professionals working in the field.

Completed questionnaires were also received from the Head-teachers and/or Special Educational Needs Coordinators of 205 schools from across Northern Ireland, 46% of whom had one or more children with AS currently enrolled.

Figure 1: Age of Young People who Participated in the Review



¹92% had a child with AS aged between 10 and 18 years inclusive; the remaining 8% had a child with AS aged 9 or under.

2. Findings of the review: Young people's perspectives





Findings of the review: Young people's perspectives

2.1 Living with Asperger Syndrome

When the 35 young people who participated in this Review were asked to share two things they found hard about having AS, the key themes arising from their responses were:

- Making friends (*"I can't be sociable"*);
- School life;
- Bullying/teasing;
- Controlling emotions (frustration, anger, mood swings, depression);
- Knowing you are different;
- Understanding people and them understanding you; and
- Attitudes of other people (*"the way 'norms' treat us"*).

When then asked to identify any advantages to having AS, the issues raised were:

- Good concentration;
- Being smart;
- Good understanding;
- Truthfulness; and
- In one instance, the fact that *"people tend to take more care of you"*.

When asked to write down 3 things they would tell another child about AS, young people's responses were, on the whole, more negative than positive (as categorised by the Review team). Out of a total of 78 statements, 22% were positive, 23% were neutral and 55% were negative.

The positive statements young people made about AS related primarily to intellectual ability. The neutral spoke of how young people with AS were different (though not necessarily better or worse) than their

peers, whilst the negative focused on lack of social skills, difficulty making friendships, behavioural traits, emotional difficulties and bullying/teasing. Examples of each of these can be seen below:

Positive

- "[You] can be smarter than others"* (10-12 year old)
- "You react to things very quickly"* (13-15 year old)
- "A memory that amazes people"* (16-18 year old)
- "Specific knowledge within a particular field of expertise"* (16-18 year old)

Neutral

- "[It] affects learning and behaviour"* (10-12 year old)
- "You say it how it is"* (13-15 year old)
- "I don't think like they do"* (13-15 year old)
- "You take things literally"* (16-18 year old)

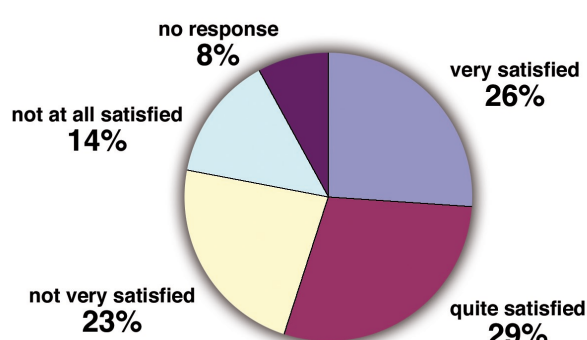
Negative

- "Find it hard when you meet other children, to mix with them"* (10-12 year old)
- "Sometimes it is hard to know what people mean"* (13-15 year old)
- "The inability to understand oneself and others"* (16-18 year old)
- "Bad behaviour"* (10-12 year old)
- "You are arrogant...get angry a lot"* (13-15 year old)
- "It can get awfully depressing"* (16-18 year old)
- "People make fun of you"* (10-12 year old)
- "You will get bullied a lot"* (10-12 year old)

2.2 Experiences of School/College

Young people were asked to rate their experience of school/college, on a four point scale ranging from very satisfied to very dissatisfied. Their responses are presented in Figure 2.

Figure 2: Young People's Satisfaction with School / College



Whilst it is encouraging to note that over 50% of the young people were either 'very satisfied' or 'quite satisfied' with their school/college experience, these figures should not be viewed complacently, in light of the corresponding fact that 66% of young people said that they would like their school or college experience to be significantly different.

Young people's suggestions for how school/college could be improved centred around the following themes:

- **The need for staff who understand AS:** 57% of young people said that teachers were 'not very good' at knowing how to help children with AS. It should however be noted that, in spite of this, most young people still felt that at least one teacher had been of help to them:²

"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" (15 year old);

- **The need for more support within the school environment;**

² 86% of young people said their teacher had helped them either 'a lot' or 'a little'.

- **The need to educate other pupils about AS:**

"There should be talks in schools about Asperger syndrome so that people understand better" (17 year old)

"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'" (11 year old); and

- **The need to effectively address bullying and create a safe learning environment:** Bullying/teasing was, by far, the most recurrent theme in young people's responses to the statement 'my worst experience in school/college has been...', with answers including *"being called names"*, *"people hit me"*, *"I got picked on"* and *"I was bullied"*. Whilst these statements relate primarily to treatment by other pupils, several young people also made reference to being put down, ignored or shouted at by teachers: *"they single me out and put me down"*, *"they just ignore me"* and *"they started on me for not understanding work"*.

Other telling responses to the statement 'my worst experience in school/college has been...' include *"there is not enough space to describe every minute I spend there"*, *"I have been humiliated too many times to pick out just one experience"* and *"do you have a week?"*

Equally telling are some of the responses to the converse statement of 'my best experience at school/college has been...' which include *"[when I] missed the school trip"*, *"changing schools"*, *"when I finished"*, *"getting out of school"*, *"never had one – barring leaving"* and *"are you ***** kidding me?"*



Although there were many negative aspects of school life identified by the young people, there were also several positives. Positive responses to the statement ‘my best experience at school/college has been...’ include school trips, extra curricular activities, “becoming a Prefect” and “getting a classroom assistant to help me”. Friendships at school were also commonly identified as a positive aspect of the school environment, with 63% of young people identifying these relationships as a positive feature in their lives.

2.3 Support for Young People with AS

“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?”
(17 year old)

Friendships (both inside and outside school) and family relationships were identified as the 2 primary sources of support for young people in this Review:

- All young people identified their family as a key source of support, with 86% saying they had been helped ‘a lot’ by their family and the remainder saying they had been helped ‘a little’.
- 80% of young people also identified friendships as a key source of support, with 54% saying they had been helped ‘a lot’ by friends and 26% saying friends had helped ‘a little’.

Although most young people were able to identify individual professionals who had helped them (teachers, classroom assistants, psychologists, doctors) they were not, generally speaking, positive about the overall level of services and support provided to them by statutory bodies. 57% rated services and help for children and young people with AS in Northern


Ireland as ‘not very good’, whilst only 26% rated them as ‘good’ or ‘quite good’:³

“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” (17 year old)

³ The remainder replied ‘don’t know’ or offered no response.

3. Findings from the review: Parents/ Carers' perspectives





Findings from the review: Parents/ Carers' perspectives

3.1 Diagnosis

60% of parents said their child had not been diagnosed until late primary (9 to 11 years) or post primary school age, with the most common age for diagnosis being 11 years of age.

56% of parents said that their child had another diagnosis in addition to that of AS. Some of these conditions are known to have an association with an ASD, such as epilepsy, but others did not (e.g. diabetes or heart condition).

40% of parents said they were either very satisfied (15%) or quite satisfied (25%) with the diagnostic process. 58%, however, said that they were 'not very satisfied' (29%) or 'not at all satisfied' (29%) with the diagnostic process.⁴

At least 10% of parents had paid for a private diagnostic assessment, as they had become frustrated with the waiting times and/or had not been in agreement with the opinion of local professionals.

Both those who were satisfied and those who were dissatisfied with the diagnostic process, raised a number of issues that they felt needed addressed. These included:

- **The fact that a satisfactory diagnostic experience appears to depend more on a parent's knowledge, skills and personal contacts, than any system strengths:** *"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"* (parent of a 10 year old, diagnosed 4 years ago);

- **Waiting times for diagnosis:** Some parents in this Review referred to 3 and 5 year delays in receiving a full assessment;
- **Lack of co-ordination between services:** *"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...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"* (parent of a 14 year old, diagnosed 3 years ago);
- **Statutory bodies reluctance to accept a private diagnosis** and the consequent requirement for a second (statutory) diagnosis in order to access statutory services;
- **The intensity and complexity of the diagnostic process:** *"It was a very intensive afternoon...We felt in shock almost, and numb, the next day"* (parent of 6 year old, diagnosed 3 years ago); and
- **Lack of written information at the stage of diagnosis:** *"I never received a comprehensive (or any) written report...It would have been useful to read over a diagnostic evaluation after receiving a verbal diagnosis"* (parent of an 18 year old, diagnosed 9 years ago).

3.2 Support Post Diagnosis

A key negative raised by many parents was that of inadequate support post receipt of a diagnosis:

⁴ 2% did not respond to this question

“Now we had a diagnosis, but we were left for [a] month on our own wondering how to move on”
(parent of a 6 year old, diagnosed 3 years ago)

“The diagnostic process was quick, but we were left on our own afterwards and there was no follow up service available” (parent of an 11 year old, diagnosed 1 year ago)

“I was just told what my child had and nothing more. I have had no help from anyone” (parent of a 9 year old, diagnosed 1 year ago)

3.3 Schooling

80% of parents said that their child attended a mainstream school or college.

71% of parents said they were either ‘very satisfied’ or ‘quite satisfied’ with their child’s current school or college placement (though it should be noted that some of these parents had previously removed their child from another school where their experience had been far from satisfactory). 25% said they were ‘not very satisfied’ or ‘not at all satisfied’; the remaining 4% did not answer. Examples of comments made by parents include:

“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” (parent of a 10 year old)

“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” (parent of a 14 year old)

“All the support provided by the school system has been driven by me. This has been immensely challenging and caused friction within the school”
(parent of an 11 year old)

“There is poor accommodation to my son’s condition. The expectation is that he fits in, not for the school to accommodate him” (parent of a 13 year old)

Issues that parents in this Review identified as contributing to a supportive schooling environment include:

- Training for staff;
- Dedicated classroom assistance;
- Good pastoral support structures within the school;
- Working in partnership with the parent and child; and
- Input of the Autism Advisory Team.

Conversely, issues that parents identified to be barriers to a satisfactory school experience include:

- A lack of understanding on the part of both staff and pupils;
- An unwillingness, on the part of staff, to accommodate the specific needs of the young person with AS;
- Reluctance to engage with the Autism Advisory Team;
- Restricting a child’s school hours on the basis of the availability of a classroom assistant; and
- Inadequate support at key transition points, including the transfers from primary to post primary and school to college/work.



3.4 Parental Concerns

When parents were asked to identify their biggest concerns regarding their child at the current time, the key issues raised included:

- Helping them understand their condition;
- Their lack of social skills and consequent isolation;
- School life, and in particular key transition times;
- Bullying;
- Anxiety, depression and/or self harm;
- Their safety;
- Other people’s perceptions;
- Lack of support from statutory services; and
- Concern about their future.

3.5 Support for Parents and Other Family Members

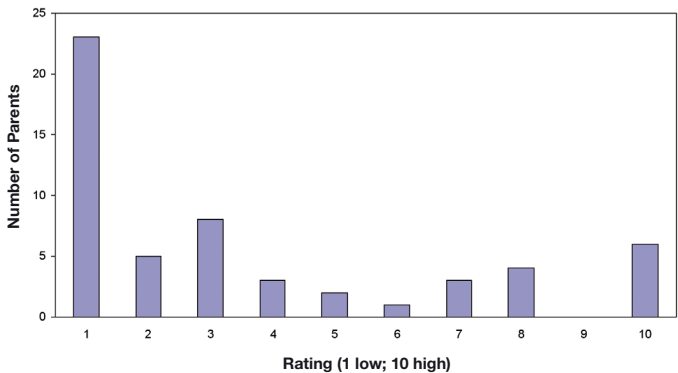
The key forms of support that parents identified receiving, and benefiting from, were financial allowances, literature to read, parent support groups and support groups for children.

Generally speaking, parents said they received only limited support from statutory services. Most said their main source of support had been that provided by existing voluntary sector organisations (in the form of literature, parent support groups and child support groups) or that which they had sourced or established themselves.

When asked to rate who/what, from the sources of support they had received to date, had been most helpful to them 17% of parents replied ‘no-one/ nothing’. 36% mentioned a specific professional, whilst 43% mentioned a voluntary sector agency.

When then asked to rate on a scale from 1 to 10 (1 being very dissatisfied and 10 being very satisfied) their overall satisfaction with the level of help and support they were currently receiving, 42% of parents opted for the lowest rating possible (very dissatisfied). A further 33% (75% in total) gave a rating in the bottom half of the scale (illustrated in Figure 3).

Figure 3: Parents’ Satisfaction with Help and Support Currently Received



4. Findings from the review: Professionals' perspectives





4.1 Schools' Perspectives

82% of the schools and colleges who had students with AS on their roll could identify improvements over the last 3 years, both in terms of their understanding of the condition and what they could offer in response. The specific areas in which they identified improvements were:

- Knowledge and awareness of the condition and its implications for the child and their parent(s);
- Opportunities for, and availability of, training - both in school and externally: 87% of schools who had pupils with AS on their roll said that staff had received relevant training;
- A desire to work in closer partnership with parents and moves towards realising this; and
- Increasing recognition of the value of Classroom Assistant (CA) time.

81% of schools, who had pupils with AS on the roll, felt that their school currently met the needs of these individuals either 'very well' (28%) or 'quite well' (53%). A further 7% acknowledged that they did not really meet the needs of their pupils with AS, whilst the remaining 12% said it varied according to the individual pupil.

29% of schools, who had pupils with AS on the roll, said that they felt they consulted with these pupils very well. A further 45% felt they consulted on some issues, whilst 26% felt they consulted rarely or not at all.

87% of schools, who had pupils with AS on their roll, said that they had received advice, primarily from their local ASD Advisory Team, on how to best support these individuals. Support and advice also came from educational psychologists and voluntary sector organisations and through the provision of classroom

assistance, however, several respondents referred to the fact that they had learned and developed their expertise by working with the student in the school.

Although schools were generally fairly positive about their responses to AS, they were still able to identify a number of concrete areas which, if addressed, would further improve the service they offered. These included:

- 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;
- Better partnership working with parents; and
- Increased capacity of advisory services.

4.2 Other Professionals' Perspectives

The key areas in which professionals working in health and social services identified a need for further development 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 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 are 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 and a mental health disorder; and
- The existence of pockets of good practice and the need for these to be shared and extended.



5. Key findings and recommendations



Key findings and recommendations

5.1 Prevalence of Asperger Syndrome within NI

It is not possible, given current diagnostic and recording practices, to establish the exact numbers of children and young people with AS within Northern Ireland or elsewhere in the UK. This has serious implications in terms of both the planning and provision of services. Ways to share information should therefore continue to be developed, where this would be beneficial for children and their families. Consideration should be given as to how best to move from the current situation of overlapping agency specific databases to the development of one comprehensive database, to which all agencies in health, education and social services contribute and have access.

Statistics compiled by the Department of Education (DE) reveal significant variations in the prevalence rate of AS amongst pupils in the 5 Education and Library Boards, ranging from 18/10,000 in the NEELB to 42/10,000 in the SEELB (DE, 2006). It is likely that this variation in incidence is closely related to variations in diagnostic practices and this should be further explored and addressed.

Though historically there were only minimal numbers of primary school aged children diagnosed with AS, this pattern appears to be changing. Statistics from DE reveal that there are now proportionately greater numbers of children with AS within the primary school sector than the post primary school sector (DE, 2006). This is likely due to increased awareness and earlier diagnosis of the condition, which holds significant implications for the cumulative numbers of children and young people requiring support and services in the future. Evidence based, and well-resourced, forward planning is required to ensure that increased demands on services can be adequately accommodated in the future.

5.2 Diagnostic Issues

Both parents and professionals within this Review identified ongoing difficulties with the diagnostic process. Particular reference was made to the need to reduce waiting times, different practices within different areas and the need for more resources to support young people and their families both during and after diagnosis.

Diagnostic procedures need to be standardised, as far as possible, across all Board and Trust areas, in line with recommended practice (Four Board Paper, 2002; NIASA, 2003; SIGN, 2006). Serious consideration should also be given as to how waiting times could be reduced, adequate information given to ALL families involved in the process and follow-up consultations accommodated.

Professionals should also be mindful of the dilemmas and issues associated with sharing a diagnosis of AS with a child or young person and supporting them and their families in deciding whether or not to disclose the diagnosis to peers, teaching staff and other key personnel. There is a need to recognise that different responses are appropriate at different times and for different people and to ensure that adequate support is in place to enable the child or young person (and their family) to make the decision that is right for them at the time.

5.3 Supporting Children and Young People with AS

Individuals with AS have diverse needs. Services therefore need to be comprehensive and adaptable enough to meet the specific needs of ALL individuals at ALL stages of their lives.

That said, there are a number of identifiable areas where almost all children and young people with AS will experience some degree of difficulty and thus require some degree of support. These are:

- communication (both their own and their understanding of others);
- social and emotional understanding and inclusion with their peers;
- flexibility in thinking and behaving;
- problem solving skills and ability to ask for help;
- relaxation;
- management of anxiety/anger; and
- daily living skills.

It is imperative that adequate and appropriate services be both available and accessible to support children and young people in their negotiation of these difficulties. The strengths, skills and interests of children and young people should also be a part of all assessment practice and acknowledged and maximised in any intervention to enhance motivation and self-concept.

Children and young people in this Review also drew particular attention to a lack of understanding of their condition and frequent experiences of teasing and bullying.

Sensitive awareness training for both peers and professionals is key to addressing the lack of understanding, and consequent social isolation, associated with AS. This is particularly pertinent within the school environment where children and young people spend so much of their time.

Interestingly, despite the fact that bullying or teasing was one of the key issues raised by young people

in this Review, this was not an issue raised by the schools. Staff in schools must be made aware of the high probability of a young person with AS experiencing teasing or bullying within the school environment and ensure appropriate measures (including a strong and effective anti-bullying policy) are in place to address this.

5.4 Supporting Parents/Carers of Children with AS

One of the key messages emerging from parents/carers in this Review is that of inadequate support for both themselves and their children. Additional support structures need to be put in place across NI, with particular attention paid to the provision of support/services out of school hours and during school holidays and ensuring equality of access to services for all (in terms of geographical location, costs etc).

Many different 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 co-ordination is therefore vital. All those involved with a child or young person with AS should consider the roles and knowledge of other key personnel involved in their lives and endeavour to present a coherent and streamlined programme of assessment and intervention to the young person and their family. Some form of key-working system may be an appropriate solution to this difficulty.

5.5 Statutory Responses to AS

It is important to acknowledge the developments and improvements that have taken place in recent years with regard to the statutory sector's response



Key findings and recommendations

to children and young people with AS. It is equally important, however, to identify areas where further developments are required.

The establishment of ASD Advisory Teams in each ELB, for example, has been a very welcome development, as has the increased provision of classroom assistance within the school environment. However, the increasing numbers of children and young people being diagnosed with an ASD (AS or otherwise) means that both these services are becoming stretched beyond capacity. Consideration needs to be given as to how the caseloads of these advisory and support services are best managed and their resources used most effectively.

A further welcome development is the self reported increase in awareness of, and knowledge about, AS amongst school staff and other professionals. Yet, in spite of this, a key theme arising from professionals within this Review was the need for further training. It would be beneficial to conduct a thorough training audit in order to accurately map (a) what training is available in each area and who this is open to, (b) what funding is available, and (c) who has availed of this training and to what degree. Strengths and weaknesses in the current structure could then be identified and a regional training framework developed on the basis of this information.

The Department of Education (2003, 2005), the 5 ELBs and Autism NI have all produced some excellent resources and training materials for teaching staff and other professionals in recent years, on the basis of recommendations from earlier reports. The 5 ASD Advisory Teams have also each produced their own packs for parents containing leaflets on local services, useful strategies, checklists to identify strengths and weaknesses, websites and articles on AS and advice

on how to look after themselves as parents. These are all very welcome developments, yet still parents and professionals have identified a need for further information. It is therefore important that both the information available, and the means by which these are disseminated, are evaluated in terms of how effectively they are meeting the needs of those who require the information.

It is clear from this Review that there is a continued role for the voluntary sector within NI, in terms of meeting the needs of children and young people with AS and their families. The voluntary and statutory sectors therefore need to continue to work together, liaising to ensure that what they offer is congruent and avoiding repetition and confusion for families. Where voluntary sector agencies are providing key services that the statutory sector is not and the worth of these services has been proven, consideration should be given to publicly funding the continuation and/or expansion of such services.

There is also a clear need for enhancing and disseminating good practice across Boards and Trusts, so that services for individuals with AS and their families will become geographically more consistent and comprehensive in future years.

5.6 NICCY's Recommendations

On the basis of the findings of this Review, the Commissioner has identified eight key areas in which action is urgently required. These are presented as recommendations below.

Recommendation 1:

The Minister for Health, Social Services and Public Safety and the Minister for Education should work together to ensure that an effective and comprehensive system is developed for collecting and collating data on the numbers of children and young people with AS within Northern Ireland. This information must then be used to effectively inform the planning of services that adequately meet the needs of children and young people with AS.

Recommendation 2:

The Minister for Health, Social Services and Public Safety and the Minister for Education should work together to ensure that a common framework for the assessment, diagnosis and management of AS is developed and universally applied across Northern Ireland. The Ministers should also ensure that clear guidelines are developed for both professionals and parents/carers on recommended referral pathways and target timeframes for the diagnostic and statementing processes.

Recommendation 3:

The Minister for Health, Social Services and Public Safety and the Minister for Education should work together to ensure greater coordination of services between health, social services and education, with the aim of improving access to, and provision of,

services for children and young people with AS and their parents/carers. Particular attention should be paid to ascertaining the views of children/young people and their parents/carers when planning what services are required and how these should be accessed and delivered. Particular attention should also be paid to ensuring effective auditing mechanisms are both in place and appropriately utilised.

Recommendation 4:

The Minister for Children should establish a cross-departmental Working Group to consider how best to address the frequent social exclusion experienced by children and young people with AS. Particular attention should be paid to the high incidence of bullying within schools, the transition from school to training or work and participation in play and leisure activities. Explicit consideration should be given to the development and implementation of a public awareness raising programme in an effort to increase understanding and acceptance of the condition. Reports on this work should be overseen by the Ministerial Sub-Committee on Children.

Recommendation 5:

The Minister for Health, Social Services and Public Safety should ensure the inclusion of specific measures in the Family Support Strategy that address the needs of parents and families of children with AS. Such services must be comprehensively available, appropriate and accessible, non-stigmatising and clearly shaped and informed by consultation with potential service users and their families.



Key findings and recommendations

Recommendation 6:

The Chief Executive of the Education and Skills Authority (ESA) must address the high demand on current educational support services, such as the ASD Advisory Teams, giving due consideration as to how best to enhance the capability and effectiveness of these services in responding to increasing demand.

Recommendation 7:

The Chief Executive of ESA and the Chief Executive of the Health and Social Services Authority (HSSA) should commission an evaluation of the appropriateness and effectiveness of current information sources/resources relating to AS, including those developed by ASD Advisory Teams, and where gaps are identified commission the development of further resources.

Recommendation 8:

The Chief Executives of ESA and HSSA should commission a training audit in order to identify strengths and weaknesses in the current structure and, on the basis of these findings, develop and implement a regional training framework for personnel in regular contact with children and young people with AS.





NICCY has three main tasks. These are to make sure children know about their rights, research those rights and problems, and take action to help when children's rights are being ignored or underplayed.

If you have a complaint about the way a child is being treated, or if you require further advice on how to engage with children, please contact us:

By phone: 028 9031 1616

By e-mail: info@niccy.org

By the internet: www.niccy.org

Or by writing to:

NICCY,
Millennium House,
17-25 Great Victoria Street,
Belfast BT2 7BA

You can also contact us by Minicom on 028 9031 6393, or by using the Relay Services to contact NICCY's telephone number (028 9031 1616).

Please contact the Communications and Participation team at NICCY if you require alternative formats of this material.

ISBN 1-905-71904-3



9 781905 719044

.....
CarbonNeutral[®] publication