

Department *of* Education

A Report on

**A SURVEY OF PUPILS WITH
ASPERGER SYNDROME**

**in primary and secondary schools
in northern ireland**

1999-2000

eti
The Education and Training
Inspectorate



INVESTOR IN PEOPLE

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1. INTRODUCTION

- 1.1 The purpose of the survey is to indicate to the education system in Northern Ireland the possible numbers of pupils with Asperger syndrome in mainstream primary and secondary schools in the Province, to evaluate the level and effectiveness of present approaches to meet the needs of this pupil population, and to identify areas and resources which require improvement and development.
- 1.2 The Education and Training Inspectorate (ETI) carried out the survey in 1999-2000, and it included classroom observations, interviews with relevant staff including the Special Educational Needs Co-ordinators (SENCOs) and a small number of parents, discussion with some pupils, and a review of relevant literature. Consultation was also held with the Education and Library Boards' (boards') special education officers, the principal educational psychologists, and a number of educational psychologists with specialist interest in the subject. In all, 24 schools were visited (see appendix), and those pupils with Asperger syndrome were observed during a variety of lessons.
- 1.3 The inspection focused on those pupils who were identified through the statutory assessment process as being within the autism spectrum disorder (ASD) continuum, and regarded as having Asperger syndrome.
- 1.4 The inspection process and procedures were considered carefully, and discussed with the special education officers of the area boards. A proforma was prepared to aid the collation of information, and to ensure accuracy and consistency in the judgements made. The proforma reflects the widely accepted characteristics of Asperger syndrome, and was tailored to elicit information about the appropriateness of teaching, and the level of awareness and training of those staff responsible for, or in close contact with, the pupils with Asperger syndrome. Evaluation was based on classroom observation, and from the descriptions of progress recorded by the schools both in meeting the pupils' educational needs, and their specific needs arising from Asperger syndrome.

1.5 In all instances, the pupils were not identified, or singled out, during the process. Many of the pupils with Asperger syndrome were questioned within the context of speaking to a number of other pupils. The pupils were not asked about their condition, and the inspectors did their utmost to ensure that the pupils, the teachers and the parents were comfortable with the survey.

2. THE DEFINITION OF ASPERGER SYNDROME

2.1 There is no easy definition of Asperger syndrome; a pupil with the condition can respond quite differently in different situations and over time, and the condition itself varies greatly from pupil to pupil. A number of characteristics do, however, predominate and these include:

- impairment in the ability to interact socially and to form relationships;
- impairment in communication and aspects of language;
- impairment of imagination and rigidity of thought.

2.2 Pupils with Asperger syndrome frequently rely on obsessive routines and narrow interests to help them feel secure, and to provide them with some control over the confusion they experience in the world around them. In addition, some pupils suffer from associated difficulties such as dyspraxia or epilepsy.

2.3 For the purposes of this survey, the focus on Asperger syndrome, as a distinct condition, is determined by the assumption that the label will assist the understanding of the condition, act as a signpost to further assessment, and indicate possible approaches to teaching and learning.

3. SUMMARY OF FINDINGS

3.1 DIAGNOSIS AND PREVALENCE

3.1.1 In Northern Ireland, there are 342,895 pupils attending mainstream primary and secondary schools. The area boards' figures indicate that there are approximately 160 pupils who have been officially diagnosed as having Asperger syndrome. The boards' figures for mainstream schools give an approximate ratio of 5:10,000, which is at the lower end of the figures suggested by various research findings.

3.1.2 The breakdown of the figure of 160 across the boards is as follows:

- Belfast Education and Library Board (BELB) - 39;
- South-Eastern Education and Library Board (SEELB) - 56;
- Southern Education and Library Board (SELB) - 28;
- Western Education and Library Board (WELB) - 33;
- North-Eastern Education and Library Board (NEELB) - 4.

The figures reveal wide variation among the area boards and suggest variation in the diagnostic approach to this condition. For example, the figure given by the NEELB, with a pupil population of approximately 65,000, represents an approximate ratio of 0.6:10,000 which is significantly below the recognised estimates. By contrast, the SEELB, with a pupil population of 66,785, records an approximate ratio of 9:10,000. The figures generally fall into the lower end of nationally recognised ratios, and suggest that the condition is not widely recognised in Northern Ireland. It is the view of the inspection team that present numbers appear to be significantly underestimated in the Province as a whole.

3.1.3 At the time of the survey, only one area board had compiled data electronically on children with autism, and the Department of Education (DE) does not currently hold a database indicating numbers of pupils by category or disability. A recent study¹ highlights a survey of 84 Health Authorities in England and Wales, the area boards in Northern Ireland, and Social Service Departments in England, Wales and Northern Ireland, and the findings show just over 17% of the services have collated data on the incidence of autism spectrum disorders. A further 38% have some very limited data, while the remaining 45% have no data. The findings of the inspection survey confirm that there are problems collating numbers within and across the area boards.

3.1.4 While the numbers of pupils identified with Asperger syndrome in Northern Ireland are low, the boards report a continuous rise in the numbers of pupils with autism, particularly at the pre-school level. Opinion as to why there is an increase in the number of pupils identified with autism varies; it is generally accepted that the system of identification is improving in response to a notably higher profile of the condition in recent years. The evidence from a range of studies indicates a growth in numbers of pupils with autism in a number of countries. This trend is paralleled in Northern Ireland, and is confirmed by this survey, though figures in Northern Ireland remain comparatively low. The strategic planners at area boards and DE level need to consider the implications of the increasing numbers in respect of current provision and resources. There is a need for a DE and individual area board database to collate information to support strategic planning.

3.1.5 The problem of confirming figures as an accurate reflection of the Asperger population in Northern Ireland is compounded by the difficulties of identification, the general lack of inter-agency collaboration, and the inconsistencies within and across the area boards in dealing adequately with the assessment of the condition. The findings of the survey confirm two important facts: first, there is confusion among the professions as to who should carry out the diagnosis, and second, making the diagnosis then takes an undue length of time. It is clear from

¹ *Thrower 2000; independent research study*

the responses provided by area board personnel that there is currently little concerted effort within and amongst the boards to address the issue of identification of the syndrome at a policy level, in order to establish protocols and procedures to direct resources and provision. There are a few examples where health and education personnel have established useful arrangements to consider the issue of identification and provision. However, these examples are the exception, and have not yet sufficiently influenced policy or planning at a senior level to ensure that Northern Ireland develops a more efficient and effective system to meet the needs of children and young people with Asperger syndrome.

- 3.1.6 Evidence from the ETI's survey of psychology services across the five area board reveals a varied pattern relating to the issue of diagnosis. There is a growth in the development of multi-agency assessment clinics across the boards, and a general acceptance that such provision can initiate or confirm the diagnosis of Asperger syndrome. Moreover, an increasing number of educational psychologists are using the multi-disciplinary model to refer children suspected of having Asperger syndrome, while a minority of educational psychologists, more skilled and experienced in working with pupils with autism, use the assessment clinic to confirm their assessment. This is further evidence that there is no consensus on who should confirm the diagnosis within and across the boards. In the WELB, for example, the Psychology Service is working on a document to guide autism assessments, and in the Londonderry area the Service has developed effective collaborative multi-agency links to promote and confirm early diagnosis. The area boards acknowledge that some psychologists are not prepared to diagnose Asperger syndrome and, in addition, mention the variation among Health Trusts, some of whom are content to identify the condition while others will not do so.

- 3.1.7 The survey also reveals an anxiety among teachers which is directly related to the confusion they meet when dealing with different health and education personnel. It is notable that in areas where there is an established arrangement for inter-agency collaboration, the number of pupils diagnosed is higher, and provision thereafter much more structured. There is a need to

ensure that the pursuit of consistency within the area boards should be mirrored by a similar development across the boards, and between Health Trusts and the area boards. The issue for schools is the extent to which referrals are based consistently on a confirmed referral model and agreed procedures. The need for consistency in respect of diagnosis is an issue to which the DE, in conjunction with the area boards, should give consideration. The issues relating to definition, diagnosis and consistency represent, in the view of the inspection team, a significant challenge that the Department and the area boards have to address jointly.

3.2 THE QUALITY OF PROVISION

3.2.1 The quality of the provision noted during the survey varied considerably. In general, it ranged from satisfactory to good; in a few instances, the practice observed was of excellent quality and, in one case, the needs of the pupil were not being adequately met. It is evident that the majority of teachers are coping well with the pupils, and the support to schools from the boards' curriculum and advisory service (CASS) is developing steadily, and is a strong and emerging feature of provision. The quality of the work of the advisory officers and of a small number of psychologists with expertise in autism, is of a very high standard and provides a model of good practice. This would seem a positive feature in light of the severity of the condition in many of the cases observed. Alongside this good practice, a number of weaknesses in the provision were noted:

- 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 Asperger syndrome;
- many teachers consider the problem is largely one of providing access to 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;
- teachers generally are still working without the continuous guidance and support which they need to cope with pupils with Asperger syndrome.

In summary, provision is largely effective in practice, but loosely knit and unco-ordinated. As a consequence, the schools, and the boards do not have a clear indication of what constitutes good practice, and what features constitute effective teaching approaches for these pupils. There is a need for written guidance, including planning and evaluation strategies, and practical exemplars.

3.2.2 The Educational Psychology Service directs support to schools. A majority of schools receive occasional input from the boards' support services, often on an informal basis at stage three of the Code of Practice. Further statutory assessment is often a means of getting the support of a classroom assistant or help from the advisory or peripatetic service. In general terms, the schools feel they can turn to the area boards for advice and support, and the quality of support for the individual pupil and his/her teacher/s is regarded as good by the schools. In addition, the schools regard highly the work of the classroom assistants. Nevertheless, a number of schools consider that the intervention provided by the area boards is not sufficiently consistent to encourage the school to take the issue forward at a whole school level.

3.2.3 In a minority of instances, teachers expressed anxiety that their intervention to help the pupils with Asperger syndrome might be of the wrong kind. In all other cases, the teachers felt that they were doing their best, but welcomed the opportunity to make requests for more effective support to confirm their efforts as helpful and productive. In all schools, there was a caring and empathetic approach to the pupils, and the inspection findings confirm that the majority of teachers dealing with these pupils were giving considerable time and attention to support the pupils in mixing with their peers, and in maintaining

satisfactory progress. In describing their needs, the teachers indicated that they require:

- advice about the Asperger condition, and the implications for teaching;
- advice about the specific needs of the pupil in addition to his/her curricular needs;
- advice about how to deal with behavioural, and, in the case of older pupils, emotional problems;
- advice about how to support parents, and help them access appropriate support from other agencies.

The teachers expressed a desire for in-service training as a prerequisite to teaching pupils with Asperger syndrome. They also expressed a need for a booklet on the subject which contained essential information on the condition, and on practical approaches in the classroom. They stressed the need to be able to avail of more expert guidance to help set their minds at rest about their efforts, and provide them with ongoing training to enable them to deal with the pupils' changing needs over a period of time. The area boards CASS service 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 addition, a number of teachers requested the opportunity to meet with other teachers who were working with pupils with Asperger syndrome. This request to facilitate teachers' meetings, including CASS, to share experiences of working with pupils with Asperger syndrome, is a practical suggestion, and would clearly be of help to teachers.

3.2.4

When the social behaviour of pupils with Asperger syndrome was a significant issue in class, requiring the intervention of the teacher, many teachers were unsure as to what they could or should do. In practice, the focus of the teachers' work was mainly target-setting in response to behavioural problems. Less attention was given to the overall social/emotional development

of the pupils, particularly for the older pupils, where the evidence of the ETI survey indicated a rise in stress and feelings of isolation. In those instances where support was available from an advisory teacher with a specialist interest in autism, due attention to the pupils' social and behavioural issues was more marked. In these instances, education plans included targets for encouraging positive classroom interaction, and the schools reported improvement in the pupils' social behaviour over time. Written reports recorded less frequent or serious temper tantrums or outbursts as the pupil progressed through the school.

3.2.5

On balance, the schools gave insufficient attention to planning specifically for the social and emotional needs of pupils with Asperger syndrome. Many of the older pupils felt isolated in school especially during break time, and during physical education. In some schools, the teachers felt that the pupil was progressing satisfactorily when he/she worked and participated well with the other pupils during lessons; in these instances, out-of-class circumstances were seldom considered. In some schools, class work was also a problem for the pupils: they felt stressed when lessons lacked structure, and the teacher's instructions about activities were confusing. A few of the pupils were reported as displaying serious signs of depression, and visits to a clinical psychologist were not uncommon among a small number of the pupils surveyed. This development was a major concern for some parents, and was, to some degree, in contrast to the priorities of the teachers. Parents reported that their children were particularly tired on returning from school, and often were stressed and exhausted. Worry was associated with isolation and lack of friends. A few of the schools, however, were mindful of the pupils' sense of isolation, and did attempt to provide regular counselling support. Two schools, in particular, adjusted their pastoral arrangements entirely to suit the needs of a pupil with Asperger syndrome, and were found to provide an excellent climate of support to which the pupil responded very successfully.

3.2.6

The evidence would indicate that the pupils need time out from class to deal with stress or classroom tiredness, and to receive individualised support. It is clear that the stresses related to the condition should, where appropriate, be explained to the pupils,

and counselling support provided to enable them to deal with the difficulties they may experience.

3.2.7

There was considerable variety in the pupils' social behaviour, in the written presentation of their work, and in the ways they coped with the teachers' use of language. The pupils had a strong desire for detail, and often focused on aspects of lessons which were not intended by the teachers. In one example, a pupil interrupted the teacher many times to ask for explanations of what was meant by "looked young for her age." While the teacher coped excellently with the interruptions, the example, among others observed, illustrates the difficulties posed by the Asperger condition, and the pressures placed on teachers to think carefully about the language they use.

3.2.8

The main descriptive features of pupils with Asperger syndrome observed during the survey conform generally to the descriptions of various leading writers in the field. What is notable are the changes in characteristics which occur with age and intervention. In the majority of instances, the reports of temper tantrums were restricted to the younger primary-aged pupils. The reports of inappropriate, frequent, blunt and cheeky remarks were more common across the age groups, and were frequently the cause of concern and confrontation between the pupil and the teacher. In discussion, the teachers reported that this type of behaviour reflected problems of communication, the pace of the lessons and, on occasions, an attempt to disturb lessons for a variety of reasons including attention seeking, fear of change or inappropriate expressions of humour. In a number of instances, the pupils failed to understand the instructions accurately, and the over-literal interpretation of some of the teachers' instructions led to the pupils failing to follow the overall direction of the lessons. However, in the majority of lessons observed, the pupils responded well, and the following strategies were the key to success:

- the teacher knew the pupil well, and had a good idea of the pupil's condition;
- the teacher was confident in dealing with the pupil;

- the teacher told the pupil what was acceptable behaviour and why;
- clear strategies were apparent when interruptions occurred;
- care was taken to explain clearly the lesson content, and visual support was often included;
- good advice was provided by the advisory officer.

In these instances, the teachers had a good knowledge of Asperger syndrome and, generally, of autism. Most had read about and researched the condition. Many had done this from a position of frustration in dealing with the child over a lengthy period of time. Those schools which had previously enrolled a pupil with Asperger syndrome felt most confident, and reported that the previous experience was the key to success. There is currently no forum at which this experience can be disseminated to other schools. In many of the schools, the classroom assistants provided valuable and unobtrusive support during breaks.

3.2.9

Where pupils were found to be more settled in school:

- classes were small;
- the classroom assistant provided effective support;
- the ethos was caring and positive;
- lessons were well-structured;
- a variety of teaching strategies were used.

A significant finding of the survey was that the pupils were more at ease in a school setting where their needs were considered at whole-school level, and the staff had an agreed set of strategies to encourage the pupil to interact positively with their teachers and peers, and to seek assistance when needed. Another

significant factor which contributed to good practice was the importance of a consistent teaching approach and a highly structured environment of routines, particularly for the younger pupils.

3.2.10

The findings of the survey confirmed that the younger pupils settled in response to a constant routine, and most teachers reported that the children were happy and friendly. The following strategies were reported as vital when teaching the younger children with Asperger syndrome:

- the teacher repeated instructions, and ensured that the pupil knew what to do;
- the classroom assistant focused the pupil's attention on the task;
- the teacher used visual prompts;
- the teacher explained the instructions to help the pupil interpret correctly;
- the teacher gave individual support;
- the lesson had a logical flow and the learning outcomes were clearly apparent;
- the adults praised the pupil, and encouraged group or paired work.

3.2.11

The older pupils settled best when the rules were interpreted flexibly, and accommodated the pupil's needs. It was frequently the case that the pupils related better to adults than to their peers. The majority of the pupils had not made friends with more than one other pupil; a significant minority had no friends. It was common to find that the pupil's class group protected him/her from the intolerance of the general school population. It was reported that, where there were instances of bullying of a pupil with Asperger syndrome, the bullying took

place in the playground, and at free time, and involved pupils who were not in the same class as the pupil with Asperger syndrome. The latter's playground routines were characterised by remaining isolated or participating only with members of the pupil's own class group. When attempting to play with others, difficulties occurred because of the pupil's misunderstanding of the rules of games which were generally team games and competitive in format. The evidence indicates that support for these pupils is often absent during free and play-time and, more significantly, little is done by schools to ensure improvements in this aspect of the pupil's school life.

4. FEATURES AND ISSUES: RECOMMENDATIONS

4.1 The main findings of the survey are:

- Northern Ireland has a growing number of pupils with Asperger syndrome, yet there is no data base to collate information about these pupils, diagnosis generally takes an unduly long time, and is inconsistent across and within the five area boards;
- parents do not receive the support they need;
- in the vast majority of schools, there is evidence of careful organisation and good practice which offers a useful starting point for the collation of examples of effective approaches;
- where schools operate a restricted notion of what constitutes appropriate intervention, the pupils' needs are not dealt with adequately;
- external support available to schools is variable in quality and frequency;
- in-service training for teachers on approaches to Asperger syndrome is highly valued, but overall, is sporadic, short-term, and not given a high priority.

4.2 A number of important and significant avenues of development, however, are emerging which are promising for schools and parents. These include:

- the recognition across the area boards that there is a need to give this condition a higher profile and additional resources;
- the introduction of advisory support at stage three of the Code of Practice for special educational needs;
- the developing skills and knowledge of the Education Psychology Service, including a trend toward specialisms in areas such as autism;
- the rise in inter-agency approaches;
- the availability of courses to support the development of knowledge and skills relevant to diagnosis and intervention;
- the developing skills of a small number of teachers with experience of working with pupils with this condition.

4.3 Throughout this survey, a number of features and issues have been highlighted which relate directly to the practice found in schools. The recommendations listed below address the main issues and concerns noted in the report, and reflect necessary changes required at school, area board and DE level.

AT SCHOOL LEVEL

The survey recommends:

- a whole school policy approach to pupils with Asperger syndrome;
- the development of an ethos which favours the needs of pupils with Asperger syndrome;

- the development of a system to ensure that the short and long term needs of the pupils are identified and met;
- a programme of in-service training to support teachers and classroom assistants;
- an effective home-school liaison programme.

AT BOARD LEVEL

The survey recommends:

- a review of existing practices to effect improvements;
- the development of a range of support which schools can access, including establishing networking arrangements amongst schools;
- the establishment of a clear and comprehensive policy to direct effective assessment;
- the creation of an electronic system to collate information in respect of these pupils;
- the development of arrangements to evaluate the effectiveness of provision;
- the development of collaborative arrangements with the appropriate agencies which support the needs of this group of pupils;
- the allocation of sufficient resources to ensure adequate training and in-school support.

The area boards also need to ensure that there is consistency in the diagnosis of Asperger syndrome, and that appropriate provision is made for the children and young people identified. The Regional Strategy Group and the Principal Educational Psychology Group are well placed to carry out this task.

AT DEPARTMENT LEVEL

The survey recommends:

- a set of guidelines to inform provision;
- the introduction of an electronic system, compatible with that of the area boards, to collate information in respect of pupils with Asperger syndrome;
- the allocation of resources to support the boards in meeting the assessed needs of these pupils;
- the creation of a research grant to a nominated body to develop a practical guide for teachers and parents;
- the continuous monitoring of provision to ensure its effectiveness.

5. CONCLUSION

5.1 The findings of the survey indicate that pupils with Asperger syndrome in mainstream schools are generally progressing well; most are happy and friendly. The teachers with teaching responsibility for pupils with Asperger syndrome cope well, in general, with the challenges such pupils present. The teachers are supported by the area boards' advisory service, which is steadily growing in expertise in this area, and which already provides good support in some instances. However, the survey identifies a number of weaknesses which need to be addressed if provision is to improve and meet, more effectively, the specific needs of all pupils with Asperger syndrome. The survey finds the Asperger syndrome is not widely recognised in Northern Ireland, there is wide variation in the diagnostic approaches within and across the area boards, and there are inconsistencies in dealing adequately with the assessment of the condition. It is hoped that this report will bring provision for pupils with Asperger syndrome into clearer focus, and assist the DE, boards, and schools to assess their practice and, where necessary, take the steps required to effect improvement.

SCHOOLS INCLUDED IN THE SURVEY

Academy PS, Saintfield
Ballycarrickmaddy PS, Lisburn
Ballykelly PS, Ballykelly
Brooklands PS, Dundonald
Drumachose PS, Limavady
Dungannon Integrated Secondary
Glenwood PS, Belfast
Holy Family PS, Belfast
Holy Family PS, Magherafelt
Killen PS, Castlederg
Lisnagelvin PS, Londonderry
Lisnagarvey HS, Lisburn
Meanscoil Feirste, Belfast
Omagh County PS, Omagh
Rathenraw Integrated PS, Antrim
Sacred Heart PS, Dundrum
St Anthony's PS Nursery, Craigavon
St Colman's HS, Strabane
St Columb's College, Londonderry
St Malachy's College, Belfast
St Mary's Boys' PS, Rostrevor
St Patrick's HS, Dungannon
St Patrick's College, Maghera
St Paul's HS, Bessbrook

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