



The Educational Experiences of Students with Asperger Syndrome

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ABSTRACT

The Ministry of Education's policy, *Special Education 2000* (SE 2000) was intended to promote a model that ensured all students received an education that involved successful experiences (Ministry of Education, 1996). Students with Asperger Syndrome (AS) often have difficulty adapting to and achieving these successful experiences in their educational environment. This paper summarises the findings from a research project that was designed to investigate the issues that arise for students with AS, determine whether or not these experiences are generally positive or negative, and examine to what extent teachers have knowledge of AS. Data was gathered from interviews with three students, their parents and their teachers and a survey to examine teacher knowledge. Data was also gathered from nine interviews and twenty-nine questionnaires. This paper reports on the data gathered from the interviews. The emerging issues were: Difficulties accessing the curriculum, social difficulties, misunderstanding of parents' roles, teacher responsibility, bullying, lack of teacher aide support, placement difficulties and sensory and environmental factors. The study concluded that the educational experience of the students was generally negative. The level of teacher knowledge was low, although the majority of teachers expressed an interest in gaining further knowledge.

INTRODUCTION

In the last few years in New Zealand the significance of AS has been recognised. It is only now that research is taking place which will identify effective teaching practise that will enable students with AS to have more successful educational experiences. This project was undertaken as a contribution towards the research of effective practise in the classrooms of New Zealand schools.

According to Tony Attwood, (1998) the prevailing view of Asperger Syndrome is that it is a variant of Autism and a Pervasive Developmental Disorder. That is, it affects the development of the student across a wide range of abilities. The characteristics of AS vary between each individual in degrees and unique combinations (Ministry of Education, 2000; Tsai, 1997). Diagnostic criteria include difficulties in the areas of social communication, social interaction and social imagination (Cumine, Leach & Stevenson, 1998). There are also difficulties in motor co-ordination skills (Attwood, 1998). As diagnostic procedures are improving, more students are being identified with AS (Tsai, 1997). In a study in 1993, Ehlers and Gillberg indicated the incidence of AS to be around one in 300 children (cited in Attwood, 1998). There is some discussion that this may be a conservative estimate and the incidence may be even greater (Attwood, 1998; Bauer, 1996; Myles & Adreon, 2001; Tsai, 1997).

The majority of students with AS are educated in regular classes in New Zealand, where an inclusive education philosophy determines that all classrooms will have an array of diversity. In this environment some students require additional support (Stainback & Stainback, 1990; Rymer, 2002). In the Education Guidelines for Implementing Special Education 2000, Special Education is defined as "...the provision of extra assistance, adapted programmes or learning environments, specialised equipment or materials to support young children and school children with accessing the curriculum in a range of settings" (cited in Rymer, 2002. p. 5). Students with AS have been identified as needing the provision of 'Special Education', (Attwood, 1998; Ministry of Education, 2000) and therefore it is imperative they are provided with the means to access the curriculum in their classrooms. At the time of this research there was very little literature available on the experience of students with AS and that of their parents and teachers in regular classroom settings. The inclusion of AS students in the everyday classroom environment although common in New Zealand is less common overseas.

From the author's experience in Special Education in New Zealand, there is a critical gap between the needs of the students with AS and the support provided to enable equal access to the curriculum. Therefore the issues that arise for these students and their parents and teachers need to be identified and addressed.

THE RESEARCH PROCESS

The project had specific aims:

1. To identify the major issues and factors that emerge as significant for students with AS in their educational experiences and setting.
2. To identify whether the educational experience has been positive or negative for students with AS.

The research questions included:

1. What are the common issues that emerge from the educational experiences of students with AS?
 - What is the nature of these issues?
 - Are they generally positive or negative?
2. How is the educational experience of students with AS influenced by:
 - a. Teacher knowledge of AS
 - b. Social difficulties experienced by the student
 - c. Environmental factors
 - d. Learning difficulties

The original research project had two phases. The first phase involved interviewing three students with AS, their parents and teachers. The transcripts were recorded and reported verbatim. There were nine participants in total. The students were boys aged 12, 8 and 6 years. The names of the students have been changed to protect anonymity. The pseudonyms are Peter, Daniel and John. The research sample was obtained through the local Asperger and Autism Support group and participants were chosen to represent a cross-section of ages and school environments. The students had all received a medical diagnosis of Asperger Syndrome. The second phase involved a questionnaire which was distributed to teachers at the schools at which the participant students attended. This paper will report on the first phase of the research.

RESULTS

Eight common issues were identified.

These were:

1. Accessing the curriculum
2. Environmental and sensory factors
3. Social skills/friendships
4. Teacher Aide support
5. Parents role and relationships
6. Teachers role and responsibilities
7. Placement difficulties
8. Bullying

1. Accessing the Curriculum

It is necessary to make some major adaptations to how the curriculum is presented to allow students with Asperger Syndrome to access it successfully (Attwood, 1998). Peter's mother pointed out the implications of Asperger Syndrome for him:

"He would be a bit more up there with what everyone else is doing if he were normal. He would know routines and be doing what the others are doing, like writing and reading, opening his lunch box and things. I don't think he would be a genius but he tries the best with what he's got... Everything he does is going to take a lot more effort. He needs directions for everything, like sit on a chair, pick up your pen. Then there's all the step by step stuff before he can write. It just takes so long. He needs to have someone direct him for all of that" (Parent 3).

People with AS are often intelligent and talented (Attwood, 1998). A person with little knowledge of AS may assume there is no disability and the person is being 'naughty' when in reality they are reacting to stress or anxiety or are unable to communicate their needs effectively. It is not unusual for a student with AS to be a very able reader or mathematician, but be unable to write their ideas down on paper, to sequence their thoughts or to express an informed opinion on a subject that holds no real interest to them. Teacher instructions are commonly perceived as meaningless by students with AS. Resulting non-compliance can cause a level of frustration both from the student's and the teacher's perspective that can be intense and the cause of much anxiety.

"I don't think he has any learning difficulties really. Just that problem with his writing. He's a bit lazy though. He'll avoid doing anything he can but sometimes he'll do some really great stuff" (Teacher 1).

"When he is tired he tends to get stressed and agitated. He doesn't like it when things don't go his way. He likes routine but he likes to do what he wants to do, he wants to set the routine" (Teacher 3).

Access to technology such as a laptop or Alpha-Smart has given students with AS with fine-motor and organising difficulties the opportunity to succeed. A resistant attitude to the provision of this support is common as the student who needs it is often very competent in other areas.

Students with AS may find it difficult to make the transition from one area of the curriculum to another (Attwood, 1998). The use of strategies such as visual schedules assists the student to cope but this requires some knowledge on the part of the teacher. Preparing the student for change by the use of visual schedules or timers can be effective in reducing anxiety but can also increase anxiety if the student is worried about completing a specific task in the time allowed. The student may be more concerned with the schedule or timer than with the activity they are expected to complete (Cumine, Leach & Stevenson, 1998).

Physical Education appeared to be a source of anxiety for one student. It was not uncommon to find the student 'forgetting' his PE gear whenever he could get away with it.

"If I could change anything I'd take PE out of the picture because it's a major cause of stress" (Teacher 1).

An alternative programme to develop skills and learn the rules of the games could assist the student to feel more confident and able to join in the class programme.

Two of the three students indicated that they would like to leave school and be educated at home. They both indicated it would be easier for them to learn if they didn't have the distractions of the classroom to contend with.

2. Environmental /Sensory

Hearing sensitivity is characteristic of AS (Attwood, 1990). All three students indicated a problem. It is difficult for students with this sensitivity to focus and remain on task if they are in a noisy environment.

"That's why I get earache. It hurts my ears" (Daniel). "I'm always sitting at the front and that's annoying. I'm forced to sit there. I get too distracted. There are too many loud noises at the front" (John).

Sensory sensitivity with touch, light, smell and taste commonly causes difficulties in the classroom. Teachers need to be aware of seating arrangements to cater for light, noise and visual distractions. Difficulties with eating, particularly at a younger age, can affect lunchtimes. For Daniel, lunchtime was so unpleasant he didn't want to discuss it at all.

3. Social skills/Friendships

All students in the study had difficulty working with others, as the following teacher quote indicates,

"I don't usually work him in a group because he can't seem to get it done, although he's OK working with just one other boy. He tends to take over a bit though."

All nine participants emphasised the importance of friends. The three students mentioned the fun they had with friends. Attwood, (1990) stresses the importance of helping to find friends with common interests and suggests friendships with other children with AS with similar areas of special interest are worth exploring. It is important to provide the assistance to promote these friendships and to develop the necessary skills to communicate and maintain relationships (Howlin, Baron-Cohen & Hadwin, 1999). The dissonance of wanting to belong but not being able to understand what is required to do so, may easily create a situation where the student with AS finds school a very negative environment in which to spend their days. Also the anti-social behaviours and frustrations that arise from the syndrome may be sufficient to prompt the school to reject the student. Although AS may be regarded as undesirable, special talents or interests as a result of the syndrome may provide increased social acceptance (Attwood, 1998).

4. Teacher Aide support

Seven of the nine participants stressed the difficulties arising from a lack of teacher aide support. Generally interventions require some form of 1-1 support either by a skilled specialist or a teacher aide who often develops the most supportive relationship with the student (Cumine, Leach & Stevenson, 1998). It is surprising then to note that in some cases the teacher aide was excluded from IEPs. The lack of support was a major issue to emerge from the transcripts and was seen by teachers and parents alike as the answer to many of the difficulties their children have in accessing the curriculum. Daniel's parent noted,

"I think he's doing OK but he could be doing better. If an avenue could be found for him to succeed I think a lot of his anxiety would go. He's got the ability. He under-achieves, has distractibility, inability to focus. He has really poor organisational skills. He focuses on the detail rather than the big picture. Perfectionism is a real problem. I think we should give them more support and teacher aides. They need more flexibility and more choices. The schools should be able to use more funding to be flexible with. Most of the Asperger kids are not ORRS funded" (Parent 2).

All three teachers expressed frustration at not being able to provide the specific programme they thought the students should be having. Peter's teacher commented, *"Time. He needs a lot more time... one on one than the other children do"* (Teacher 2).

The source of special needs funding support for students who are in regular classes in New Zealand is generally limited to the Special Education Grant (SEG), Ongoing Reviewable Resourcing Scheme (ORRS) and Learning Support funding (LSF). Resource Teachers of Learning and Behaviour (RTLb) are frequently involved but the needs of AS students are generally not recognised as severe enough to attract individual funding such as ORRS.

5. Parents Role and Relationships.

All three parents were advocates for their children's support and actively involved in the IEP process. They had developed an extensive knowledge of AS. All expressed concern over staff attitudes toward them. The parents had played an important role in providing information, but the general perception of the parents was that they were not appreciated as supports. Two teachers stated the students would benefit from less involvement with their parents at school. One mother, discouraged by the teacher from being in the classroom, reluctantly kept her distance. All parents wanted to be more involved with providing information and skills for the people involved in teaching their children.

6. Teachers Role and Responsibility

Parents all felt the teacher's responsibility was to provide a special programme that met the particular needs of their child. They expected the teacher to be interested enough to want to learn. They wanted the teacher to provide a safe environment to teach social skills to the student.

Communication about what was happening at school was also a high priority as the parents thought the students were unable to give enough information. One parent stated, *“My major concern is communication between home and school. Peter won’t tell me what is happening. I can only tell by his behaviour”* (Parent 3).

The students expected the teachers to keep them safe from bullying by doing something about the other students. There was a high correlation between positive student comments and relationships with teachers. *“It feels good when you meet someone who does understand you”* (Daniel). *“I like Mr Greg cos he keeps everything the same and doesn’t change anything”* (John).

The teachers’ main expectations for themselves revolved around meeting the students’ academic and social needs. They were all concerned with learning about the syndrome and were considering the student’s special needs e.g. seating, noise levels and curriculum expectations. All teachers felt there was more they should be doing.

7. Placement

All three students had a negative start to their educational experience. The difficulties Peter’s parents had finding a suitable placement for him started at pre-school. They then visited seven schools before choosing Manu. John’s parents moved him to a different school after the first year. At the time of the interview they talked about moving to another city to find somewhere where his developing needs would be addressed. Daniel’s parents had moved him to several schools and at the time of the interview were resigned to the level of support he was receiving.

“The first four years were terrible, lots of problems. I transferred him to another school. That was much, much better. They concentrated more on trying to meet Daniel’s needs rather than trying to fit him into the model they were presenting” (Parent 2).

There are very few placement choices for parents who have children with special needs in New Zealand other than the regular classroom. However, the needs they have will not be addressed in a regular classroom without support. The parents all expressed sincere concern over their options and two of the students expressed an interest in being educated at home. All three parents considered social and friendship needs as more critical than academic priorities when considering placements, although opportunities for academic achievement were important also.

8. Bullying

Bullying was a major problem to the students and is in one case the main focus of his school memories.

“My school life is mostly negative because all throughout my school life I’ve been bullied, bullied, bullied. And I’ve been the number one person who’s been picked on. The teachers didn’t do anything at my old school. I was tortured. I used to hide” (John).

The teacher of this student comments that a major problem this student has is that he ‘winds’ the other boys up and calls them names. Although it is difficult, children with Asperger Syndrome can be taught appropriate means of managing and preventing bullying (Attwood, 1990).

POSITIVE AND NEGATIVE EXPERIENCES

As well as the eight themes resulting from the research, a number of common positive and negative experiences were also identified. The common positive experiences were: friendships, computers, being listened to, teacher aide help, playing with others, sharing achievements, joining in, learning how to resolve conflicts, positive feedback from teachers, the library, reading books, favourite teachers who share common interests, art, information technology, poetry, science experiments, practical work and quiet desk time.

The common negative experiences were: bullying, writing, being left out, aggression, group work, lunchtime, noise, teasing, distraction, incomplete work, losing gear, anxiety, getting angry, change in routine, harming others, mathematics, too many rules, lack of understanding, no friends, eating lunch, not being liked, bright sunlight, confusion in class, the uniform, name calling, sitting at the front, boredom, fitness and PE, depression, school bells, taking turns, no space to yourself, no teacher aide support and teachers misunderstanding.

INFLUENCE OF TEACHER KNOWLEDGE

As well as identifying the common issues in relation to the educational experiences of students with AS, this study also sought to find out how the educational experiences of students with AS were influenced by their teachers’ knowledge of AS. As accurate identification of AS is relatively new in New Zealand, the level of teacher knowledge is not high. There is therefore much to be done in the area of professional development. According to Attwood, (2000) the prevalence of AS is relatively high, 1/300 students at least, therefore 1/10 classrooms (based on 30 students per class) or most schools will have at least one student with AS. Teacher knowledge is critical in the management of AS as correct interventions are necessary to achieve success (Cumine, Leach & Stevenson, 1998; Howlin, Baron-Cohen & Hadlin, 1999). In this study, parents were more concerned with the teacher’s attitude rather than the depth of their knowledge. However all three teachers were concerned with their lack of knowledge and were unsure how or where to remedy this. Having these students in their classes had generated curiosity about the syndrome.

“I wasn’t aware Daniel had Asperger Syndrome until the first IEP. I was led to believe there was actually not much wrong with him that a bit of discipline wouldn’t fix. I’m quite interested in finding out a bit more” (Teacher 2).

Two students in the study indicated a good understanding of the syndrome but only one teacher thought to seek further information from these students. Both students knew very clearly what would enhance their educational experiences.

"I try to tell them but no, they won't listen to me". Many students with AS are articulate and it may be a useful strategy for teachers to ask the students what is happening for them and apply this information to their practice.

There has been an effort by the Ministry of Education and the National Autistic Association to provide training to Resource Teachers of Learning and Behaviour and thereby increase teacher knowledge. The next important stage is to acknowledge the need for resourcing to support that knowledge.

CONCLUSION

The purpose of this paper is to discuss the educational experiences of AS students and the level of teacher knowledge of AS. The findings have shown that student experiences were generally negative. The emerging issues of concern are: Difficulties in accessing the curriculum, environmental and sensory complications, social communication and interaction difficulties, lack of teacher aide support, communication between parents and school staff, lack of teacher knowledge and confidence, placement difficulties and bullying. Teachers generally had little knowledge of strategies to manage the students although most teachers surveyed were interested in further training. Teachers did not ask students directly for information to improve their practice or knowledge. Lack of academic achievement and poor social interactions were of concern. Lack of teacher aide support was a major issue with access to funding very limited. The impact on the classroom is high with other students having little empathetic understanding of AS. Although the parents and teachers identified the deficits in the students, the students themselves had little understanding of the part their attitudes and behaviours played in the problems. Teacher, student and parent perspectives were often very different.

The results indicate there is much work to do towards improving the educational experience for these students. There is growing awareness of AS and the need to adapt the system and provide funding support for this to happen. It is the responsibility of educators to provide an environment that gives these students their best chance to achieve. Problems are often behavioural, but these students are generally not deliberately 'naughty'. Effective strategies and interventions are not difficult but they are also not typical of other behavioural strategies (Howlin, Baron-Cohen & Hadlin, 1999). Social skills programmes for the students and access to support and technology are areas that need focus to improve the educational experiences of students with AS. Information gathered directly from students with AS, their families and teachers must be used in the development of educational supports. Further research on the actual outcomes of the educational experience for AS students would be helpful.

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PERSONAL PROFILE

I am a Resource Teaching Learning and Behaviour who is regularly working with many students with Autistic Spectrum Disorder and their families. I have a special interest in Asperger Syndrome in the school environment and have worked in the field of Special Education in New Zealand for many years. I am also the parent of a son with Asperger Syndrome who was diagnosed at the age of 14 years.

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RESEARCH QUESTIONS AND DATA COLLECTION

A. What are the common issues that emerge from the educational experiences of students with Asperger Syndrome?

- What is the nature of these issues?
- Are they generally positive or negative?

Parent:

1. Tell me about your experiences with X educational experience.
2. What involvement do you have with X school and teachers?
3. What are some of the main difficulties X has at school?
4. What are some of the more positive factors involving X school experience?
5. How has AS affected X at school?
6. If you could change anything to do with school what would it be?
7. How would you go about changing things to make the educational experience better for X.
8. Is school generally a positive or a negative experience for X?

Teacher:

1. Tell me about having X in your classroom.
2. What specific difficulties or concerns have you noticed X has with school?
3. What particular aspects of school do you feel X enjoys?
4. Were you aware X had AS prior to my contact with you?
5. What changes if any did you need to make in your classroom or teaching style?
6. What differences have you noted in X needs compared to other students?
7. What contact do you have with the parents/caregivers of X?
8. Describe any issues you have with having X in your classroom?
9. Have you received any extra support with X in your classroom?
10. What, in your opinion could improve the educational experiences of students with AS.
11. Is school generally a positive or a negative experience for X?

Student:

1. Tell me what it is like in your school.
2. What are some of the cool things about being at your school?
3. What are some of the things that are not so good?
4. If there was something you could change to make your school better what would it be?

5. What would you keep the same?
6. What difference does having AS make to you at school?
7. Is going to school fun?
8. If it's not, what would you rather do?

B. How is the educational experience of students with Asperger Syndrome influenced by:

1. Teacher knowledge of Asperger Syndrome
2. Social difficulties
3. Environmental factors
4. Learning difficulties

Parents:

1. Does X teacher know about AS?
2. Have you had any meetings with X teacher about AS?
3. How has X teacher found out about AS?
4. Does X have friends at school?
5. Does X have difficulties getting on with the other students?
6. Does X relate better to the adults in his school environment than other students?
7. Does he have friends home from school?
8. Are there any special relationships X has with other students or teachers?
9. Does X receive any extra support at school?

Teacher :

1. What prior knowledge did you have of AS before X came into your room?
2. What training have you had in Autistic Spectrum Disorder?
3. Where did you gain your knowledge of the disorder?
4. Do you think you need further information or training?
5. Where do you think you could get further information when you need it?
6. What specific support have you received for X?
7. Have you noted any difficulties between X and other students?
8. Does X work well in group work?
9. Does X have friends at school?
10. What does X do at lunch-time?
11. Where in the room is X seated?
13. What type of work environment does X prefer?
14. What difficulties, if any have you noted in the classroom environment?
15. Does X have any other learning difficulties in addition to those you know are related to AS?

Student

1. Does your teacher know about AS?
2. Do other students know you have AS?
3. How does this make a difference?
4. Do you have any favourite teachers?
5. What makes them your favourite?
6. What do you do if someone is annoying you?
7. Tell me about lunch-time at your school.
8. Do you have friends at your school?
9. What sort of things do you do with your friends?
10. What do you do when you need help?
11. Are you happy about where you sit in class?
12. What do you do when you need help in class?
13. What would your ideal classroom be like?

C. How is academic achievement affected by the above factors?**Parent:**

1. Do you feel X is achieving well at school?
2. How do you think AS impacts X achievement?
3. What do you think could improve his achievement?

Teacher:

1. Do you feel X is achieving well at school?
2. What are the factors that limit his academic achievement?
3. What do you think could improve his achievement?
4. What particular curriculum areas does X have difficulty with?

Students:

1. What is hard for you at school?
2. Why do you think this is hard for you?
3. What is easy for you at school?
4. Why is this easy for you?
5. What extra support would help you at school?
6. Do you do your best work in school?
7. What helps you do your best work?
8. What stops you from doing your best work?
9. Do you work well in groups?
10. Do you prefer to work on your own.
11. Do you have access to a computer for your learning?
12. How does this help you?