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Perceptions of school by two teenage boys with Asperger syndrome and their mothers: a qualitative study

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ABSTRACT

This qualitative study aimed to develop an understanding of the challenges faced by teenage boys with Asperger syndrome and their mothers. A case study approach was used to collect data from two 13-year-old boys who have Asperger syndrome and their mothers in Queensland, Australia. Data were collected through the use of semistructured interviews. The words of the boys and their mothers provide a valuable insight into the personal experiences and feelings of the participants. An inductive approach to data analysis identified four themes: (1) developmental differences; (2) problems associated with the general characteristics of Asperger syndrome (i.e. communication and social difficulties, restricted range of interests, a need for routine); (3) stress; and (4) 'masquerading'. The first three themes relate strongly to the current literature, but the emergence of masquerading is of particular interest in developing a fuller understanding of the experiences of individuals with Asperger syndrome at school.

Introduction

While much has been written about the importance of family support for students with disabilities (Turnbull and Rutherford-Turnbull, 1997), little attention has been paid to the specific challenges faced by parents with children diagnosed with Asperger syndrome, or to the views of the children themselves.

Although children with Asperger syndrome generally have relatively good verbal skills, they show many other impairments in socialization, communication and imagination (Frith, 1996; Tantam, 1991; Wing and Gould, 1979). Their uneven profile of functioning can mask other fundamental deficits and many children with Asperger syndrome have great difficulty in obtaining adequate educational support. Similarly, because of diagnostic delays parents may have to live for many years with uneasy feelings that something is wrong with their child before receiving appropriate information and support.

The school-related difficulties experienced by children with Asperger syndrome will also affect their families. How these families cope with the challenges of parenting depends on the resources, support and appropriate information available to them (Turnbull and Rutherford-Turnbull, 1997). The aim of this paper is to develop an understanding of the challenges faced by mothers of children with Asperger syndrome and the children themselves. The insights provided by the participants in this study are pertinent for teachers, parents and all involved in inclusive education.

Although there is a range of options in schooling for students with disabilities in Queensland, Australia, legislation mandates that all students can be enrolled in their local school unless there are compelling reasons for doing otherwise (Education Queensland, 1998). The boys in this study are enrolled in regular schools.

This study

This report is descriptive with an emphasis on the use of personal stories and reflections. It was planned to provide teachers with an insight into the social world of Asperger syndrome in order to give them a better understanding of the syndrome, and to assist them in teaching students more effectively. A case study approach was used to collect data from two 13-year-old boys and their mothers through the use of semi-structured interviews. This approach allowed the two individuals with

Asperger syndrome to describe their own experiences, as well as giving a voice to the mothers' recollections of their sons' development and school experiences.

Researchers such as Minkes et al. (1994) and Morris (1998) have written about the importance of empowering individuals with disabilities by seeking their views. Ethical standards for research with children were considered in planning this study, such as attention to informed consent and ethical interview procedures. These issues are similar to those discussed by Mahon et al. (1996) and Ward (1997).

Participants

Two special educators selected a student who had Asperger syndrome in their schools who would have the ability to speak about his disability and school-related experiences. The selection process was also influenced by the fact that the mothers of the selected boys were active advocates for their children and were interested in assisting teachers to develop a better understanding of Asperger syndrome. The special educators facilitated contact between the boys, the parents and the researchers. Pseudonyms have been used to protect the true identity of the participants.

Mark is 13 years old and is currently completing his first year of high school. He lives with both parents in a middle-class suburb on the outskirts of a city in Queensland. Mark is the only child of his father's second marriage and he was diagnosed with Asperger syndrome late in 1996, after an initial diagnosis in 1995 of attention deficit disorder. He attends a private Christian high school where he participates in the same grade 8 subjects as all other students. He receives some in-class support from the special education teacher for English. Mark's special interest is sport. He has successfully played a range of sports since he was 3 years old. Currently his favourite personality is Tiger Woods, about whose career Mark knows a bewildering array of facts and figures.

Noel is also 13 years old. He lives in a suburb of a large coastal centre with his mother and younger sister in Queensland. Noel is completing his last year of primary education at a Catholic school. He completes much of his academic work within a special education unit attached to his school. Noel joins a regular grade 7 class for art, religion, sport and other appropriate sessions. He was diagnosed with Asperger syndrome 9 years ago. His special interest is Apple Macintosh computers and he has profound knowledge of the hardware and software associated with these machines. Noel regularly telephones computer customer service lines to gather more information and to ask questions. He has applied for positions as a computer consultant and on one occasion was asked to travel to the nearby capital city for an interview. A representative of the interested computer company was very surprised to find out that the applicant was in fact a schoolboy.

Data collection and analysis

Once the necessary permission was obtained, the researchers provided the special education teachers, mothers and students with an outline of the interview questions. Both the mothers and the boys' teachers ensured the boys understood the questions and explained the format and aims of the research project. The boys decided themselves if they wished to be involved in the project. Both boys were knowledgeable about Asperger syndrome and its characteristics and were keen to help teachers by sharing their own personal perspectives of their school experiences. The mothers of the boys were also committed to improving teacher education in relation to Asperger syndrome.

The technique of in-depth interviewing was used to gather data (Minichiello et al., 1995). This technique is described as a conversation with a specific purpose 'focusing on the informant's perception of self, life and experience, and expressed in his or her own words' (1995, p. 61). The interviews followed a semi-structured format and lasted approximately 40 to 60 minutes. The two boys were asked to respond to the following questions: (1) Can you tell me about yourself: your age, what grade you are in at school, what you like doing, what you don't like doing? (2) Let's talk about school ... : What do you like doing best at school and why? What do you find hard and why? What does your teacher do that makes it easy for you to learn? What does your teacher do that makes it difficult for you to learn? (3) Tell me about your friends ... : Why are they a good friend?

The mothers were asked to respond to the following questions: (1) Call you tell me about your child (age, school involvement, likes and dislikes)? (2) What do you remember about the child's early years: growing up, what they most liked to play with, development and social interactions? (3) How do you help your child with learning at school? (4) How can teachers and school staff help children with Asperger syndrome?

The interviews took place at the school and those with the boys were videotaped and then transcribed, although video data were not analysed. The interviews with the mothers were audiotaped and then transcribed.

Qualitative research uses the induction model, which means that data collection may commence without any preconceived hypothesis (Wiersma, 1991) and aims to describe and explain a pattern of relationships by means of a set of conceptually specified categories (Mishler, 1990). The method of constant comparison advocated by Glaser and Strauss (1967) and endorsed by Lincoln and Guba (1985) was used in this study. This strategy combines inductive category coding with a comparison of all data. As phenomena are coded and classified, comparison also occurs across and between other categories and phenomena. In this way relationships are identified and initial conceptualizations are refined through further data collection, classification and analysis. This 'part to whole' approach takes account of many viewpoints before deriving theory.

Findings

The findings are organized into four main headings: (1) developmental differences; (2) problems associated with the general characteristics of Asperger syndrome (i.e. communication and social difficulties, restricted range of interests, a need for routine); (3) stress; and (4) 'masquerading'.

While the first three themes relate strongly to the current literature, the emergence of masquerading is of particular interest in developing a fuller understanding of the experiences of individuals with Asperger syndrome at school. Each of these areas will be described in turn.

Developmental differences

Although some parents describe close bonding and attachment with children who have Asperger syndrome (Szatmari, 1991), others report feeling that their children were always different in some way (Carrington and Forder, 1999). Mark's mother recalls that her son was aloof from babyhood:

But even from a little baby he never liked being cuddled. He was happy. He didn't sleep much, he liked people around him, spoke early, always acted a lot older.... There was always something about Mark that I could never, ever put my finger on. He never had a friend, he was never invited to play at people's places, never got invited to birthday parties.... He was just different.

As Gross (1994) has noted, the behavioural oddities of these children seem so nebulous that parents find it difficult to express their concerns about their child's early development. A quote from Noel's mum illustrates this:

Well, he was always different. He appeared to be like a normal baby. He was alert, bright, fed well, slept well.... He crawled before he sat.... His milestones were a little bit different.... He didn't concentrate.... I just knew there was something that wasn't right. People thought I was mad.

A number of writers (Attwood, 1997; Szatmari, 1991) have described the unusual play habits of children with Asperger syndrome. Their play is often repetitive and lacking in creativity and rarely promotes social interaction. According to Noel's mother:

He never played. His idea of playing was upturning a box of toys.... He always wanted to play with electrical plugs and leads. He just didn't know how to play.

Specific problems associated with Asperger syndrome

Social and communication difficulties. Children with Asperger syndrome tend to be egocentric. They have great difficulty in social situations: in particular, they often use inappropriate body language and do not appear to listen to others or recognize their intentions or non-verbal cues (Gross, 1994). Mark's mum described some of the difficulties Mark experienced in interpreting and demonstrating appropriate body language:

He can't read body language. He is always invading your space, always standing too close to you. He still goes up and tugs a girl's hair. He has no idea. So, he's classified as a weirdo by a lot of the kids. He just can't understand.

Episodes of *Mr Bean* have been creatively used to teach social skills to students who have Asperger syndrome. The hapless 'Mr Bean' is an extreme example of an individual who does not read or

respond to social situations appropriately and has difficulty taking the perspective of others. His adventures can be used to explain social situations and to help students understand how other people may feel or think in certain circumstances (Beasley, 1997). Mark's mum described another television show that provided similar opportunities:

We actually have been watching Third Rock from the Sun because we can relate to the aliens, and we're actually using that as a teaching process. Third Rock from the Sun is about a group of aliens sent to earth and they have no concept of what goes on. They have no social skills whatsoever. So Mark really relates to that. Now he's started saying, 'I really do feel like an alien sometimes because I'm in my world and all of you people aren't doing what you should be doing in my world.' So we can relate to that.

Theory of mind deficits are characteristic of autistic disorders. As being able to appreciate the thoughts and feelings of others is a vital part of developing relationships (Wing, 1996), it is very difficult for children with Asperger syndrome to establish and maintain friendships (Gross, 1994). Mark describes the difficulties he experiences in developing friendships:

Last year wasn't a good year. I didn't have many friends, I used to go home in tears actually, because I saw all the other kids with friends and when they were having trouble they could just talk to their friends and I couldn't do that for some reason. I couldn't make friends.

According to his mother, even the concept of a 'friend' seems to be unclear to Mark:

I don't think he really understands what the concept of a 'friend' is. A 'friend' to him is somebody who sits beside him and shares what he doesn't eat out of his lunch box. He doesn't understand, I think he really doesn't understand because he's never had any.

Restricted range of interests Children with Asperger syndrome have a tendency to focus on one particular interest to the exclusion of all else. They can become obsessive collectors of information and may hold forth on the topic of their specific interest at any available opportunity (Gross, 1994). Noel's obsession is with Apple Macintosh computers. The impact of this interest on his ability to concentrate at school is evident from this dialogue:

Researcher: What sort of things do you find hard at school?

Noel: Maths . . . and to stay in the classroom and to try and concentrate.

Researcher: Why is it hard?

Noel: When there is [sic] about three computers in the background and I'm sitting right next to the computers and I can't keep my eyes off them and it's hard to like stop.... One part of me says 'Go on it, go on it!!' and the other half of me says 'Don't do it! Don't do it!', and sometimes I get confused, sometimes I just explode and do the wrong thing, and sometimes I just explode and do the right thing!

Mark's obsession is very different. From the age of 3, he has participated successfully in different sports and, as his mother recalls, at one time he loved cricket:

If he became interested in playing a game of cricket, then he would play a game of cricket all the time, every day, until something new took over. We didn't realize they were obsessions at the time. It was very intense. He had to do it, at all hours of the night and day... He was obsessive.... Whenever he did something, that became the whole focus.

Need for routine

Children with Asperger syndrome may be overwhelmed by even minimal change. They may find coping with everyday life a bewildering task without sameness and routine to help them control their environment. This need for sameness was particularly evident in a description of Mark's eating habits by Mark's mother:

He has a very limited food range. He has taken chicken wings for lunch every day for 8 years to school. They have to be prepared a certain way. When we are going to McDonald's for a cheeseburger, it's got to be meat and cheese only No sauces, no pickles, no nothing. No salt on the chips. No ice in the drink. Then, when he eats the burger, he takes the top piece off the bun,

puts eight, exactly eight, potato chips into the bun, folds it over, eats it. Then he peels the cheese off the meat, eats the meat, and then puts the piece of cheese on to the bottom piece of the bun.

Likewise, Noel's mum describes her son's routine when he arrives home from school:

He likes to walk in the door to turn the computer on or he goes straight to the phone. He's got something on his mind and he has to ring. I haven't even got through the door sometimes and he's on that phone, usually an 1800 number. ... Something about information about computers. He'll either do that or go straight to the computer. Nothing else. Or he might stand in there and say, 'Who's touched my room?' He can always tell if anyone's touched anything in his office, in his area. Who's touched this? Who's been in there?

Stress

An inability to cope with or adjust to social situations often causes children with Asperger syndrome to be easily stressed and emotionally vulnerable.

Both Mark and Noel spoke of the stress they experienced at school. In particular, social interactions with peers seem problematic. This may be because both boys have difficulty interpreting subtle social cues and are becoming more aware as they grow older that they don't 'fit' (Carrington and Graham, 1999). The emotional stress associated with the basic need to belong is evident from Noel's interview:

Noel: I get stressed in the playground.

Researcher: Why do you get stressed in the playground?

Noel: Because when the other kids listen to you, they tease you. Sometimes I wish I don't [sic] have fixations and sometimes I wish I didn't have Asperger's. I wish I wasn't autistic.

For Mark, stress was also associated with completing work for school subjects, and meeting class expectations:

At night when I get home when I have to get things done by tomorrow, I have trouble. You know how kids normally just get it done? I have trouble and I leave it until the last minute and I get really worried and then when I'm worried I can't concentrate and I've kind of got to learn to concentrate and I worry.

Students with Asperger syndrome need help to cope with the demands of the regular classroom. They can become anxious and upset and may be prone to depression. In adolescence, when peer relationships are vitally important, students with Asperger syndrome have an increased need for social support and understanding. During their teens, these students generally become more aware of their 'differentness'. They want to 'fit in' but don't know how. These anxieties and need for acceptance are evident in Noel's responses:

Noel: It's really hard when the other people don't know how it feels to have Asperger syndrome. It feels quite upsetting at times and quite difficult.

Researcher: In what sort of ways?

Noel: Getting people to understand how I feel when they hurt me.

Researcher: How do you feel when this happens?

Noel: Sometimes I feel like I could just explode.

'Masquerading'

Although both boys spoke of the stress associated with completing schoolwork and meeting the social expectations of peers, their mothers suggested that many of their feelings were hidden or 'masked' in the school environment. Both parents recalled the emotional reactions and stress that were evident when the boys returned home after a day at school.

Noel's mum: An hour later at home he's firing off because of a small trivial matter, and that's when he'll say, 'You don't know what happened to me today! I've had a bad day. I'm so stressed.' And he still won't tell me what happened.

Mark's mum: A lot of people can't understand the stress business. And he hides it. They don't know that he's stressed at school. Even though these kids appear academically competent, there's so much more going on in their life. Even though the kids mightn't stress out at school they usually explode as soon as they reach the safety net at home. Then there is additional stress at home, not only on the family, but on the kids all over again.

Part of the difficulty appears to be the significant variation in ability for someone like Noel. His mother describes the difficulty that children with Asperger syndrome often have in coping with such a broad range of ability:

Unfortunately his range of functioning is so wide, I mean it's not as though he's low on everything or high on everything, he's got some aspects of both. A lot of the time he's acting like his 5-year-old sister, so immature: he cries like a baby and he demands my attention like a baby. And other times he's like disciplining me like an adult, controlling me. So it's sometimes like trying to handle a boy that's beyond his years and thinking not like a 13-year-old should think. Other times he's blowing people away with the things he comes up with.

Mark's mum spoke about the 'normal facade' which masks her son's deficits:

When you see a child who is so normal, you have doubts. Does he have it? Does he not have it? And then the next minute he does something and you know that he does [have it]. But sometimes it's so hard to realize that there is a problem. So what goes on in those times? When appearances are normal, a lot of things can happen. A lot of information should have been absorbed and processed and it hasn't been. And you forget that it hasn't been absorbed and processed properly. And a situation arises and you're going, 'But, I've already told you!' And you sort of forget.

Conclusion

This was a descriptive study with no intent of generalizing the results to all children who have Asperger syndrome. However, the words and views presented by the boys and their mothers indicate particular difficulties that could well be shared by other families with a child who has Asperger syndrome.

Three findings emerged. First, the accounts describe the specific difficulties that the boys have in forming social relationships with their peers, and in understanding, interpreting and developing friendships, in order to help improve functioning in this area.

Explicit teaching and repeated practice of social and communication skills have been recommended for children who have Asperger syndrome (Attwood, 1997). Mark's analogy with 'aliens' illustrates the difficulties that individuals with Asperger syndrome may have in understanding and coping with social behaviour and expectations. Thus it may be necessary for them to learn social skills in an intellectual manner because of their basic lack of social instinct and intuition (Williams, 1995). It should therefore be a priority to teach students with Asperger syndrome behaviours that are acceptable in the classroom and in broader social contexts (Carrington and Graham, 1999).

Second, it is evident from these interviews that the obsessions associated with Asperger syndrome can become a handicap if not adequately controlled and monitored. Noel is torn between doing what he is obsessed with and attending to his lessons in class. In the classroom, obsessions can be encouraged in socially acceptable ways. For example, Tantam (1991) suggests that obsessional interests in computers can be encouraged and used to enhance the child's social status in the classroom.

While Mark's interest in sport does not appear to impede his learning in class, his mum reports that he was more motivated when the curriculum topic focused on his area of interest. Repetitive questioning or lecturing on special interest topics needs to be monitored by the classroom teacher. Perhaps a certain period of the school day can be put aside solely for work or discussion on the special interest. Once this routine is established, the child may learn to stop asking questions or making inappropriate comments at other times (Williams, 1995).

Third, as Mark and Noel begin their teenage years, it is evident both that they are aware of 'not fitting in' and that they are trying to mask their deficits. There is considerable stress associated with this masquerading and this in turn may lead to depressive symptomatology for these adolescents (Szatmari, 1991; Williams, 1995). Teachers and parents must be aware of the pressures that young

people with Asperger syndrome experience and need to consider ways in which they can help to minimize and control stress (see also Attwood, 1997; Williams, 1995). Teachers and parents also need to be alert to any changes in behaviour that may indicate depression. Symptoms can include disorganization, inattentiveness and isolation, decreased stress threshold, chronic fatigue, crying and suicidal remarks.

Behaviour difficulties may also surface as a result of stress and the overwhelming panic that individuals may feel when events in their social world become unintelligible and unpredictable. Coping and calming strategies can be presented and practised. For example, Williams (1995) suggested that students can be encouraged to write down a list of concrete steps that can be followed when they become upset. It may also help to include a ritualized behaviour that the individual finds comforting such as tapping in time to a silent tune (Williams, 1992). Music played through earphones may also be calming. Noel spoke about using a Walkman to listen to peaceful music in order to manage his stress: 'I like listening to music. It kind of makes me calm. It cools me down.'

The accounts presented in this paper illustrate the experience of two boys who have been diagnosed with Asperger syndrome. The students' own words provide an insight into their perceptions of themselves and their school-related experiences. Their mothers also provide insight into the challenges associated with living with Asperger syndrome. We suggest that more qualitative research in the field of autism is necessary to achieve an in-depth exploration of the real-life experiences of these individuals from their own perspective.

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