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A Phenomenological Study

THE SOCIAL WORLD OF FIVE ADOLESCENTS WHO HAVE ASPERGER'S SYNDROME

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Abstract

This phenomenological study investigated the social experiences and perceptions of friendship among teenagers diagnosed with Asperger's syndrome. Data were collected through the use of semi-structured interviews from five secondary school students in Australia. Data analysis resulted in the identification of a number of recurring themes used to illustrate the words of the young people in the study. These themes and words inform the reader by providing real experience of the characteristics of people who have Asperger's Syndrome that are emerging in the growing research: (1) description of social experiences - both difficult and satisfactory (2) description of hostile encounters with peers (3) need for following rules and (4) 'masquerading'. Masquerading is a term used to describe the facade, which some individuals with Asperger's syndrome adopt in order to mask their social differences. This type of study enables professionals to enter the worlds of adolescents who have Asperger's syndrome, by describing and analyzing the social phenomena found there. Although professionals have the goal of assisting young people with Asperger's syndrome to participate in 'socially accepted ways', there is also an obligation to recognise and value different persons' social perspectives. The findings of this study could inform a more subtle approach to social skill programmes for adolescents with Asperger's syndrome.

The ever-present difficulties that individuals with Asperger's syndrome face in socialization and peer rejection throughout their lives constitute a major hurdle, influencing all aspects of their daily lives (Frith & Happe, 1999). This paper investigates personal reflections about friendship and social experiences in secondary school in order to improve our understanding of teenagers with Asperger's syndrome and inform social skill programmes for these students. Asperger's syndrome is a developmental disability marked by impairments in social relationships, verbal and nonverbal communication, as well as restrictive, repetitive patterns of behaviour, interests and activities (Barnhill, 2001a). In spite of this, their intellectual ability can be within or above the normal range.

Children who have been diagnosed with Asperger's syndrome have particular difficulties in communicating with their peers and forming appropriate relationships with others at school (Attwood, 1998). Continuing difficulties with social interactions have been found to contribute to aggression (Simpson & Myles, 1998) and depression (Barnhill, 2001b).

Asperger's syndrome may cause the greatest disability in adolescence and young adulthood because social relationships are key to many achievements at this time (Tantam, 1991). During their teens, these students generally become more aware of their "different-ness". Carrington and Graham (1999) describe the juxtaposition of the need of adolescents to "fit in" and the inability of those adolescents with Asperger's syndrome to fully comprehend social situations and thus achieve this acceptance. "Different-ness" is frequently exasperated by the types of traditional interventions that focus on changing the behaviour of the person. Well-intentioned strategies may be employed that do not account for the social-cultural context of the individual. Not surprisingly, it is during this time that clinically diagnosable depression and anxiety can

develop which may be significantly related to an evolving, painful awareness of their social differences (Ghaziuddin, Weldmer-Mikhail & Ghaziuddin, 1998; Wing, 1981).

Our professional understanding of Asperger's syndrome and the particular social difficulties in secondary school can be enhanced by endeavoring to listen to, accept, and reflect upon the voices of the participants in this study.

DESCRIPTION OF THE STUDY

This study uses interpretative sociology to provide a framework by which the researcher can enter the child's world and meanings to understand the child's own perspective (from the inside out). "This is necessary because situations, meanings, problems are defined in interaction with others" (Greig & Taylor, 1999, p.44). Data were collected from five students who had a diagnosis of Asperger's syndrome, who were enrolled in a secondary school in Australia. Semi-structured interviews were used to obtain information from the participants (n=5). This approach enabled the adolescents to describe their own experiences in an open way. Researchers such as Minkes, Robinson and Weston (1994) and Morris (1998) have discussed the importance of empowering individuals with disabilities by seeking their views. This phenomenological approach, within an interpretative sociological framework, facilitates an understanding of the participants' experiences (Patton, 1991) and advances a more holistic view of the characteristics of Asperger's syndrome. The goal of this type of research is not to explain, but to understand the "lived experience" of the adolescents as they constructed meaning from their own experiences (McPhail, 1995). Ethical standards for research with children were taken into consideration in the planning of this study. These issues, which include attention to informed consent and ethical review procedures, are similar to those proposed by Mahon, Glendinning, Clarke and Craig (1996).

Setting

This study was undertaken in a large urban secondary school in Queensland, Australia. The school provides support services for students with different teaming needs and employs two special education teachers who work in a special education support unit in the school. Services from the support unit include: assistance with organization of timetables, coordination of special education modifications and curriculum changes, support of classroom staff, advocacy for students with special needs, and communication with parents and outside agencies.

Participants

Potential participants (those students with Asperger's syndrome) were identified in consultation with the special education teachers. Information and consent packages were then sent to eight families and five families agreed to take part in the study. The students agreed to be interviewed regarding their beliefs, understandings and experiences of friendships. Characteristics of the participants in the study are summarized in Table 1. All participants have been the focus of an assessment process described as Ascertainment by Education Queensland (see Education Queensland policy document SM-15 Ascertainment Procedures for Students with Disabilities). This process requires a medical diagnosis of Asperger's syndrome either by a paediatrician or psychiatrist. The identity of the participants has been protected by the use of pseudonyms.

DATA COLLECTION

Phenomenological methods of data collection do not follow prescribed rules (Mc Phail, 1995). In this study, through the presentation of different stories from adolescents with Asperger's syndrome, the varying structures and meanings of consciousness are revealed. Data regarding students' perceptions of friendships and social experiences were collected using semi-structured interviews. The technique of indepth interviewing used to gather information for the study is described by Minichiello et al., (1995) as conversation with a specific purpose "focussing on the informant's perception of self, life and experience, and expressed in his or her words" (p 61). Five students who agreed to participate in the research were interviewed for approximately 20-40 minutes and the interviews were audio-taped for later transcription.

The interview questions were created and refined in consultation with a special education teacher from the school who was experienced in supporting students who have Asperger's syndrome. The final questions were distributed to the' parents and to each student prior to the interviews. The special education teacher at the school organized interview times and locations. The first and third authors undertook interviews over a period of several weeks. The interview questions are detailed at the end of this paper in Appendix A. Interviews were transcribed and imported for analysis into a computer software program, QSR NUD*IST

(Non-numerical, Unstructured Data Indexing, Searching and Theorising) (Richards & Richards, 1994). This software package is designed for qualitative analysis of unstructured data and assists with the storage, coding, retrieval and analysis of the text of the interviews.

Table 1: Characteristics of the participants in the study

PSEUDONYM	ALICE	JOHN	LARRY	JACK	MORRIS
SCHOOL GRADE	YEAR 8	YEAR 10	YEAR 10	YEAR 11	YEAR 12
Age at time of study	14 yr.	15yr.	15yr.	18yr.	17yr.
Diagnosis	Asperger's syndrome	Asperger's syndrome	Asperger's syndrome	Asperger's syndrome	Asperger's syndrome
Additional Assessment Information (e.g. particular strengths, weaknesses, or obsessions)	<ul style="list-style-type: none"> - Special interest in and excels at art / portraiture. - Strong spelling and vocabulary. - Easily stressed & becomes very anxious in new situations. - A perfectionist. 	<ul style="list-style-type: none"> - Particular interest in motorbikes - Poor concentration in class, struggles academically as a result. - At risk to be lead astray socially in order to be seen as one of the crowd. 	<ul style="list-style-type: none"> - Very advanced computer skills. Has inserviced school staff in areas of IT. - Perfectionist, becomes highly anxious when he does not achieve what he thinks he should 	<ul style="list-style-type: none"> - Special interest in war history and politics. - Difficulty with processing, and analysing problems - Poor social skills, few friends 	<ul style="list-style-type: none"> - Advanced skills in the food and hospitality area. - Highly developed computer skills. - Difficulties in the area of communication and social skills.
Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian
Support from Special Education Centre	<ul style="list-style-type: none"> - Visits special education . centre on an as-needed basis to relieve stress - Receives 10 hours of support from special education staff in the general education classrooms 	<ul style="list-style-type: none"> - Visits special education centre on an as-needed basis to relieve stress. - Receives 10 hrs of support from special education staff in the general education classrooms - Receives 4 hours of support in the special education class 	<ul style="list-style-type: none"> - Receives 3 hours of support from special education staff in the general education classrooms 	<ul style="list-style-type: none"> - Receives 4 hours of staff in the general education classrooms 	<ul style="list-style-type: none"> - Receives 4 hours of support from special education staff in the general education classrooms - Receives 3 hours of support for English in the special education class

DATA ANALYSIS

This interpretive-descriptive research used a data analysis approach, which is both inductive and deductive in nature. Meanings and words that emerged from the data were organized into categories, however, the categories of data were also influenced by the literature that informed the research and researchers' "preconceived notions that are part of their being" (Mc Phail, 1995, p.7). As phenomena were categorised, comparison also occurred across and between other categories and phenomena (Strauss & Corbin, 1994). A phenomenological approach respects the meanings created by the participants. In this way, "the other's" way of seeing the world is communicated through the words of the students in the interviews. Data analysis in this study involved taking these words and creating understandings about the individual perceptions of friendships and social relationships. The words of the participants themselves provide an insight and illustration of the growing published understandings about the characteristics of Asperger's syndrome.

FINDINGS AND DISCUSSION

The study findings and discussion are organized into four main themes: (1) description of social experiences - both difficult and satisfactory (2) description of hostile encounters with peers (3) need for following rules and (4) 'masquerading'. While the interview quotes in the first three themes provide examples to support the current literature, the theme of masquerading holds promise in developing a fuller understanding of what it means to live in a social world as an adolescent with Asperger's syndrome and could inform future social skill programmes. The exploration of the theme of masquerading builds on earlier work (see Carrington & Graham, 2001; Carrington, Templeton & Papinczak, 2003) that described student masking of anxiety, stress

and lack of social understanding in the school environment. Masquerading is an important factor in surviving high school because adolescents with Asperger's syndrome are aware of the need to "fit in" so they try and act in the ways their friends act and say what their friends say. Many adolescents with Asperger's syndrome become expert "people watchers" and learn the script of "the right thing to say at the right time" and "the right thing to do at the right time".

Children with Asperger's syndrome often desire friendship but the concept of reciprocity and sharing of ideas inherent in friendship is not readily comprehended (Filipek, Accardo, Baranek, Cook & Dawson, 1999). These social difficulties influence the development and maintenance of friendships and social contact with peers outside of school. In this study, Alice could provide a definition of friendship but she did not discuss her friends or socializing outside the structured environment of her school. Her dearth of social contact with friends outside of school is illustrated in the following extract:

Researcher: Do you ever go out with friends - when you are outside of school - on the weekend?

Alice: No, not often, not really often.

Researcher: Have you been out at all this year?

Alice: I've been out, but not with my friends.

Individuals with Asperger's syndrome have a tendency to focus on one particular interest often to the exclusion of all else (Barnhill, 2001a). Correspondingly it is common for friendships to develop around these shared interests. For example, the computer game of Dungeons and Dragons was central to Larry's friendships. His description of people who are not his friends included the criticism that they care more about "how their bags look on the wall" than "who is the captain of the next Dungeons and Dragons adventure." He spoke in detail of his interactions with friends in the Dungeon and Dragon club at school along with various out of school activities focused on the same interest. This game appeared to dominate Larry's social life, his spare time and his friendships. In contrast to the special interest in computer games, John's obsession was money and this interest provided a different lens to conversations about friends. He explained that he shares two main things with his friends, food and money. Money dominated many of his answers to questions about respect, trust, and friendship. He indicated that friends who don't repay money are annoying, and friends who respect him are not just after his money. He stated, "Respect in friendship means showing them that you're actually their friend - you're not just some cheapskate who just wants [their] money".

Conversational skills often represent a major impediment for individuals with Asperger's syndrome, requiring an ability to relate to and understand the mental states of others (Frith, Happe & Siddons, 1994). Alice's conversations don't really involve her participation. She listens but does not take part in the talking in a two-way interaction. While Jack strives to take part in conversations with his peers, the stress that this entails is expressively described in the following quote: Conversations are difficult because you mightn't know what to say in the conversation with no words in your head or you get stuck in a conversation and you say to yourself: "Oh! I've got to get out of this one!" or something. And these people might think you're weird, walking away or something. I don't want it to happen but I don't know how to react.

The concept of friends and friendships was also difficult for some of the students to explain in detail because there was little discussion of emotion such as affection or feelings of loyalty that are frequently associated with friendship. John's description of a friend is a good example. "Maybe it's just that they are nice to you and they're not acting mean. And you think, well, they're acting nice to me. I better act nice back or something like that."

It is important to note that the students generally indicated satisfaction with their friendships. Individuals described feeling comfortable with their friends and had no desire for any assistance with their friendships from teachers or other adults at school. While some of these friendships were based strongly on shared interests, generally these teenagers did not seek to improve or alter these relationships in any way. For example, when asked to describe a perfect friendship, Larry's response was: "The ones I've got now." John suggested that his friends are "pretty decent people" and explained how these friends helped to protect him from bullying in his early years at secondary school. Morris also described a comfortable relationship with his friends with whom he shared mutual interests. Other researchers have reported similar findings. For example, Church, Alisanski and Ammanullah (2000) described how even quite superficial friendships based solely on mutual areas of interest can provide adolescents who have Asperger's syndrome with their friendship needs. More in-depth relationships were not seen as more valuable to these people.

The social difficulties associated with Asperger's syndrome often create frustrations and problems, which may result in aggressive behaviour (Simpson & Myles, 1998). Typically viewed as eccentric and peculiar by classmates (Williams, 1995), children with Asperger's syndrome are often victims of bullying. All four boys in this study, described situations in which peers had teased them, usually in their early years of secondary school. While these descriptions are self-reports and therefore represent their own

perspective of events, it seems apparent that other students were targeting them with hostile behaviours. For instance, Larry stated that arguments with other students at his school had "forced him into hospital from something physical." Larry could also recall incidents in which peers had destroyed his property including his computer. John described episodes of teasing because he was different. "They tease you about yourself just because they are a little bit better." It is not surprising that in adolescence, when social expectations increase and peer relationships become more complex (Adreon & Stella, 2001), individuals with Asperger's syndrome experience significant degrees of bullying and peer derision. Adolescents with Asperger's syndrome need a mentor or support person in the school environment who is able to provide subtle assistance when needed in the secondary school setting. One of the most significant roles of this professional support person is to facilitate social interactions and friendships by connecting students with Asperger's syndrome with others in the school community (Safran, 2002). However, adult mediation runs the risk of blocking social relationships and further alienating the student with Asperger's syndrome.

According to Twachtman-Cullen (1997), the organizing principle of Asperger's syndrome characteristics is that "behaviour is rule-governed." The cognitive inflexibility found in individuals with Asperger's syndrome is considered an essential feature of this condition (Szatmari, 1991; Wing, 1998). Many individuals with Asperger's syndrome cannot seem to appreciate that there may be situations in which rules can be bent or broken. Alice who refuses to consider talking in class demonstrates this core feature of Asperger's syndrome: "In class when you really have to pay attention, you don't talk." She describes people who are not her friends as those "that don't pay much attention" and have to be removed from the classroom. Larry explained that those students who are not his friends "either get into trouble or get you into trouble" and Morris stated that he didn't like those students who "do things differently" or "break the law". Similarly, Jack described students who were "not friends" as students who frequently get into trouble at school. Professional support people are usually aware that membership in a peer group in secondary school is frequently determined by the willingness of peers to make accommodations with each other. So issues of "breaking the rules" can be difficult to address when developing connected relationships with adolescents. The promotion of teamwork that requires ongoing development of social skills that are integral to the learning process for all students is an excellent way to allow all students to contribute and develop personal strengths in communication.

Carrington and Graham (2001) coined the term 'masquerading' to describe the normal facade that some individuals with Asperger's syndrome adopt in order to mask their social differences. The theme of masquerading can be readily distinguished in the interviews from several of the participants in this study. In particular, John's strategy for appearing socially competent in front of his peers clearly exposes the daily struggle to appear normal.

Try and act the way your friends act when you're around them and they'll begin to like you. Just act the way other people act and they'll like you. Talk about what they like just to impress them.

I've looked at the way other people see me, if you know what I mean. I look at the way they think, think of the things that they like. I watch the way people without Asperger's syndrome act and then I try to play along with that.

John's response to a question about specific aspects of friendship included the comment that "I'm just guessing. I've noticed that in other people's friendships." Clearly, John is observing and copying the interests and behaviours of his peers in order to conceal his social awkwardness. Alice also described a similar strategy to establish friendships at school:

Researcher: If I went up to some people whom are your friends and I said to them: "What does Alice really like?" what would they tell me?

Alice: That she likes what we like.

There is stress associated with the attempts of teenagers with Asperger's syndrome to mask their social deficits in this manner (Carrington & Graham, 2001). A comment from Jack revealed the stress he feels in conversations with his peers when he strives to be accepted with his peers. When Jack stated there were "no words in your head", he described his worry that his friends might get irritated with him and think that he is weird when he "stands there and says nothing." Myles and Simpson (2001) discuss the 'hidden curriculum'- the do's and don'ts that are not spelled out for everyday behaviour but somehow everyone knows about them except those with Asperger's syndrome. Perhaps by observing behaviour and copying their peers, these teenagers are gaining an insight into the hidden curriculum that exists in their school.

Children with Asperger's syndrome have difficulty modifying their social behaviour to suit the context of the environment (Szatmari, Bartolucci & Bremner, 1989). This can lead to inappropriate behaviour and peer rejection. The theory that autistic children's social understanding is acquired through a painstaking reasoning process compared to the social understanding of normally developing children, which is achieved quite intuitively, is supported by Travis, Sigman and Ruskin (2001). This process of learning social skills and behaviours needs to be subtle for the adolescent who is intent on masquerading, to enable acceptance in the school community. Jack for example, was particularly wary in the research interviews and stated; "I don't spend much time around other Asperger's kids living an Asperger's life... I spend my time around non-Asperger's kids that do other stuff and then I get their ideas". He goes further to state, "I don't want people to know that I'm special. I just want them to know I'm an ordinary person". These types of statements alert us to the need to ensure programs of support have an inclusive focus that enhance social opportunities in the school community rather than separating students further. Larry is emphatic in saying "I want to pick my own, friends" along with Morris who says, "I don't want to make more friends". Special education teachers need to ensure that any assistance with social skilling is actually warranted for adolescents with Asperger's syndrome and if warranted, then attention needs to be focused on the social ecology of the school community.

CONCLUSION

This paper has presented insights from five students about individual perceptions of and understandings of relationships with peers, along with descriptions of strategies to enhance peer acceptance. The themes of hostile and/or difficult social experiences at school and cognitive inflexibility also flow throughout the students' perceptions of their experiences. It is significant that some of the students in the study had developed successful strategies that ameliorated bullying and aggressive behaviour from peers. Equally significant is the satisfaction expressed by these teenagers with many of their friendships. The participants spoke of feeling comfortable with friends, and of shared interests and activities. While it was apparent that their social experiences could be stressful and difficult, there seemed to be a common thread of self-perceived social success continuing through their stories.

In recent years, there has been an increasing amount of literature describing various interventions for improving social skills for children and adolescents with autism/Asperger's syndrome (e.g., Aarons & Gittens, 1998; Gray & Garand, 1993). The use of social stories for instance, has been employed to teach children with autism desirable social skills by cuing them with appropriate responses (Gray & Garand, 1993). A social skill strategy has emerged from the findings of this study, which resembles a more subtle approach where the adolescents observed and imitated the social skills of their peers in a conscious and planned manner. This subtle approach avoids the need for teenagers with Asperger's syndrome to take part in organized social skills programmes that serve to draw their special needs to the attention of their schoolmates. John explained the stigma of labeling (Szatmari, 1998) in his own words. "I don't talk about this - this Asperger's thing (with my friends). I don't even let them know I'm Asperger's." He goes on to indicate his dislike for the special unit at school that enables others to see that he is 'different' and needs 'special help'. While masquerading is stressful, it provides an opportunity for students like John to avoid the stigma of labeling and 'fit in' with his peers. While it is recognized that children with Asperger's syndrome often have a different view of their friendships and social experiences compared to their parents (Church et al., 2000), it is apparent that the teenagers in this study believe that they are having some success in their social world, at least by their own standards.

The accounts presented in this paper illustrate the experiences of five secondary school students with Asperger's syndrome. The strength of this phenomenological study is that unique experiences and perceptions, in this case belonging to adolescents with Asperger's syndrome, have the opportunity to reveal different ways of seeing the world (McPhail, 1995). We suggest that more research of this kind is necessary to achieve a more in-depth exploration and understanding of the experiences of young people with Asperger's syndrome from their own perspectives to inform future planning for social skill programmes for this group of students.

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QUESTIONNAIRE

INTRODUCTION:

The interviewer introduces herself, welcomes the student and thanks him/her for agreeing to participate. She goes on to explain the nature of the research and the confidentiality of the responses. Finally, the student is told that they can ask for a question to be repeated, refuse to give a response to a question and/or stop the session when they wish.

All questions are asked of the students. However, the interviewer may modify the wording of the question slightly to enable the student to more fully understand what is being asked of him/her.

QUESTIONS:

Tell me how you have a good time with your friends.

What do you understand by respect in friendships?

What do you think about trusting friends and keeping secrets and promises?

Some students have said that friends are those that you get along with and don't fight with. Tell me about this for you.

Tell me about how you and your friends are interested in the same things.

Tell me about how people who are not friends, are different from you.

In what way do they not match you or match your personality?

People who are not friends sometimes argue with you. Have you had this happen? Can you tell me about that?

Some people describe people who aren't friends as being difficult. Is this your experience?

Have you ever had people who are not friends tease you?

Friends are those with whom you share similar interests. What interests do you share with your friends?

What do you do if you go out with friends?

What about visiting with friends - do they come over to your house or do you go to their house?

Some people have said it is important to keep in contact with your friends. How do you keep in contact with your friends?

How comfortable are you with your friends?

Tell me about how your friends are reliable.

People have said that they're not normally nervous around their friends. Is that the same for you?

Usually friends don't criticize each other. What's been your experience with that?

Some people who aren't your friends can be annoying. Have you had any experience with people like that?

Often they might say stupid things. Tell me about this.

People who are not friends have been described as those that get into trouble. Has this been your experience?

Do you think your friends know what types of things you like and don't like?

Some people said they think their friends should know about their special needs. What do you think?

Some people have said they don't want special help with their friendships from their teachers. What do you think about this?

Are conversations difficult for you?

Confidence was something people said was important. How confident are you?

The student is then thanked for his/her participation.