ADOLESCENTS WITH ASPERGER'S SYNDROME:

A QUALITATIVE STUDY

OF

SOCIAL INTERACTION FACILITATION

BY

KATHRYN MAY WADY

A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

MASTER OF EDUCATION

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Abstract

The author of this study interviewed eight people who were personally or professionally involved with adolescents with Asperger's syndrome, asking each participant to describe Asperger's syndrome and ways of facilitating social interaction for adolescents with Asperger's. Verbatim quotes from the participants, who included an adolescent and an adult with Asperger's syndrome, are included in the thesis. The literature review gives researchers' current understanding of Asperger's syndrome. Establishing a network of knowledgeable, caring people who can act as mentors, social interpreters, and advocates, develop relationships based on trust, unconditional acceptance, and affirmation, and provide supported, structured opportunities for social interaction is described as a way to facilitate social interactions for adolescents with Asperger's syndrome.

Acknowledgements

I wish to acknowledge and thank the eight people who I interviewed and whose words and thoughts form the basis of this thesis. I would also like to thank those individuals with Asperger's syndrome who have been described in this thesis. Martin, Frank, David, Nancy, and Jane have added to my understanding of Asperger's syndrome. They are also an integral part of this thesis.

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INTRODUCTION

Asperger's syndrome is a life-limiting, social disability. An adolescent with Asperger's syndrome is like the boy in the bubble, separated from the world by an invisible barrier. Access to the world is crucial for psychological and emotional survival, and yet the invisible barrier prevents meaningful interaction from taking place. Finding a way to break through the bubble and create a safe route to social interaction will allow adolescents with Asperger's to have a healthy future. This is a study of how adolescents with Asperger's may be helped out of the bubble.

Sensing an invisible barrier is one way that professionals intuitively identify individuals with Asperger's syndrome. Teacher A described a shell, or a kind of absence, around someone with Asperger's. The person is visible under the shell, but the shell disallows easy, intuitive, human connection. It is like a plastic wrapper which prevents a connection with the person underneath. Teacher A explains the plastic wrapper analogy:

> *I see people with tremendous potential who are hindered by this overlay. They have every characteristic for success and then you throw this blanket on top of it. It's like plastic. All of those good things are there, but they're always muffled through this plastic wrapped around them.*

While real interaction is prevented by the transparent barrier, the person underneath is uniquely visible to the world. One can view the thoughts and feelings of someone with Asperger's in ways that most people do not allow. They may be identified by their unusual openness and honesty to the point of extreme naivety. They will bluntly tell you exactly what they think of a new haircut or a new person. For example, one boy with Asperger's stood up in

church and announced to his father, the minister, that the sermon was too long and that it was time for him to quit talking so that everyone could go home. Perhaps the boy who announced that the emperor had no clothes had Asperger's syndrome. Such naive honesty invites both respect and ridicule. To those who work with this community it represents both a blessing and a curse. Teacher A explains the value and honour of being able to see into someone's soul:

> *Because kids with Asperger's syndrome are verbal, you can track their thinking and feelings. You see so much of the human thinking in them because they allow you to. And you don't get that opportunity with other kids. Which is a great gift and you've got to be so careful with it, you know?*

Caring and compassion are Teacher A's reactions to the blunt honesty of individuals with Asperger's syndrome. Unfortunately, their social naivety does not invite such a humanistic response in everyone they meet. Often, individuals with Asperger's syndrome are faced with teasing, ridicule, and rejection by others when they inappropriately attempt to make a social connection. Eventually, cruel, rejecting laughter from potential acquaintances leads individuals with Asperger's to withdraw and to cease initiating social interaction. Accumulated hurt, anger, and distrust increases the barrier between individuals with Asperger's and the world. The negative results of such social naivety may be profound loneliness, dismal self-esteem, and life-threatening depression.

Teacher B presented a scenario which explains how devastating an inability to understand and enter social situations may be for those with Asperger's. I asked him to describe a social interaction which was a disaster. He related the following story about someone I will call David, an adolescent with Asperger's syndrome:

The example I would use is of a young man who has spent probably fifteen years on the periphery of social circles. He has never really had the opportunity to interact, both because of his insecurity and his lack of social skills. One day, he thought that he had learned that one way to enter social circles is to make an impression. So he came into the High School library, where all of his so-called buddies were located, attempted to do a handstand, and fell flat on his back.

Of course this unusual, inappropriate act led to large amounts of laughter from everyone who was observing. The laughter became a catalyst to an incredible amount of anger within the young man. And so his attempt to engage in a social milieu became the most embarrassing and disheartening of situations for him.

He knew, "I want to impress these individuals." But his attempt to do so quickly reverted into the worst possible situation, where he not only embarrassed himself, but he got very angry and he started to threaten people who were laughing at him.

With this devastating result to an attempt to interact socially, it is not surprising that individuals with Asperger's syndrome may eventually give up any attempt to enter social situations, deciding that loneliness is a better alternative to ridicule, acute embarrassment, and psychologically-wounding pain.

Social Interaction with Peers Prime Deficit

Not Having Friends Common for Those With Asperger's Syndrome

Adolescent A Hurt by Teasing, Becomes Cautious With Peers

When I was asking him what Asperger's syndrome meant to him and when he first became aware that he was somehow different from most other people, Adolescent A began to

describe his first experiences with being teased. Our conversation went like this:

I: *When did you first become sort of aware that you were a little bit different than most other people?*

Ad: *When was I first aware?*

I: *MmmmHmmm.*

Ad: *That's a real good question.*

I: *If you think back, when did you start thinking about it?*

Ad: *Ah, probably when those meathead kids that used to be in my neighbourhood kept calling me names.*

I: *So there were kids that were really bugging you.*

Ad: *Yeah.*

I: *How old were you then?*

Ad: *I must have been seven or eight or something like that.*

I: *You started thinking like, "Why are these kids bugging me?"*

Ad: *Yeah. Like they gave me the old traditional label.*

I: *Oh.*

Ad: *Retard.*

I: *Oh. So they were really cruel.*

Ad: *Oh, yeah. They were morons.*

Even today, as an eighteen-year-old, this young man is still suffering from the hurt imposed on his eight-year-old self by the cruel taunting of his neighbourhood peers. Those jeering comments, and probably others like them, have taught this young man to avoid

approaching others. He does not attempt to make friends. Instead he waits for other people to approach him in a friendly fashion. Even so, he is cautious and aware of the danger of *"getting burned."* When I explained that most experts see social interaction difficulties as one of the prime deficits of Asperger's syndrome and that, therefore, they would say that he would have problems with interacting with other teenagers, this young man heartily agreed. Adolescent A used his strategy of making friends as an example of how difficult he finds interacting with other teenagers. *"Well, just my basic strategy of making friends. I wait for other people to initiate things before committing myself to them."* Conceivably, this young man could wait for a long time before a peer would initiate a contact.

Others Notice Lack of Friends

Not having friends is a common experience for those with Asperger's syndrome. Each of the people that I interviewed commented on the lack of friendships for those with Asperger's. When I asked Teacher Assistant A to give an example of poor social interaction skills being a problem for those with Asperger's syndrome, she stated succinctly: *"They don't have friends. None of them have friends."* Parent A expresses the pain that she felt when she observed her son's futile attempts to enter neighbourhood friendship circles.

> *From three years of age until twelve years of age he didn't have any friends. He couldn't play on the street. Imagine you have a kid who can't walk out the door and play, when they are playing hockey on the street, when they are running around with their water pistols, and when they are riding their bikes, or whatever. He would enter and within ten minutes something would happen and he was back. So he was profoundly lonely.*

Eventually, Parent A's son, who I will call Martin, gave up. Like Adolescent A, Martin quit

trying to initiate friendships. Parent A explains:

> *It just didn't work. I mean there was always a glitch. Something happened that offended him, or angered him, or hurt him, or whatever, and he was back in the house. And eventually he just didn't leave the house. You know, eventually he just shut down.*

Adult A Aware That He Needs to Initiate Friendships

The twenty-three-year-old adult with Asperger's syndrome, who I interviewed, agreed that social contacts were difficult for him to initiate and that he, also, had *"got burned"* in the past. However, he is also very aware that he needs to initiate social contacts. When I mentioned Adolescent A's strategy of always waiting for prospective friends to approach him, Adult A commented:

> *You know that is the unfortunate thing for me right now. I think I'm not aggressive enough. And that is the trap that you can get trapped in and Adolescent A* [sic] *can get trapped in, if he just waits. You've got to let your guard down a little bit.*
>
> *And unfortunately, if you don't let your guard down at all, you may not get burned again by anybody, but you lose any chance for happiness. You lose that.*

Adult A's open analysis of his life dilemma almost moved me to tears during our interview. Although he was speaking in cliches, I sensed the profound loneliness that he must experience. I also felt the desperation that he is encountering because he knows that he must develop meaningful relationships to have any chance of happiness, and yet he has no idea of how to go about initiating a friendship. I told him that his comments were really profound. He then described the crux of his social problems and we discussed the pain that he might encounter in initiating social contacts.

A: I'll tell you the truth. I have to start dating. I have to. I don't have a girlfriend. I think I need to get a girlfriend. I think I need one. I've got to start dating. And for me to do that, I am going to have to start to take chances.

I: Yeah, you are. You're going to have to/

A: I'm going to have to take very big chances here.

I: And you are going to have to realize that you may be rejected sometimes.

A: Yes.

I: But if you don't take that chance, then no one is ever going to say yes, either.

A: That's right.

I: Yeah.

A: And that's rough.

I: But, it's a scary thing to do though.

A: Yes! And I know I am going to make that jump very soon.

I: Well, that's good.

A: Don't know how. (Laughs) But I think that might be something for Teacher B [sic] *and I to talk about.*

Inappropriate Social Strategies Lead to Rejection

Heart of Problem for Those with Asperger's

Wanting to make social contacts, but not knowing how to do so and encountering ridicule and rejection when inappropriate social strategies are used, is the heart of the problem for individuals with Asperger's syndrome. They may cease initiating social contacts, as Adolescent A has, or they may anxiously attempt to connect, as Adult A is planning to do, and risk repeated

failure and rejection. Unfortunately, their lack of social understanding may lead them to behave in ways that seem very antisocial, bizarre, and even cruel. This socially unusual, negative presentation may easily lead to rejection by acquaintances and even to the severing of long term professional relationships. Parent B explains how her daughter's behaviour is interpreted by people they encounter in public.

> *She'll do odd and eccentric things that seem very willful. And so her behaviour gets interpreted as really bad behaviour. I'm out with Jane [sic] all the time, and Jane will start yelling at me or do something that is really very inappropriate for her age.*

Difficult People to Like

The speech and language pathologist who I interviewed perceives individuals with Asperger's syndrome as being very antagonistic and as difficult people to like. She believes that people with Asperger's syndrome do not understand how their behaviour and comments may offend and hurt others. However, Speech and Language Pathologist A also believes that those with Asperger's syndrome truly want to be part of the social world, and that they are unintentionally building barriers to friendships. She explains how they inadvertently sabotage possible friendships.

> *I think that they are very difficult people to like, in general. Very difficult. I think that they know enough to be pleasant when they first meet somebody. And that can first of all fool people. So they think, "Oh, this is a plain, ordinary kid." And at the same time, within an hour of meeting that Asperger's person, that Asperger's person can just do something so hurtful to one's feelings.*
>
> *These Asperger's people don't invite. They don't invite people to be warm to*

them. Or to like them. And I do feel really, they want to be part of the world. And they just don't see how they are affecting others. Or they don't take it seriously, either. I think that they react to a person in some hostile way because of some moment in time. And they don't realize how that is affecting that other person.

Some Behaviour Seen As Cruel

Teacher Assistant A described how one student, who I'll call Frank, seemed to like to see people emotionally stirred up and how he would plot ways of causing an emotional reaction in vulnerable others, without considering the pain that he might be causing and the relationship damaging consequences of his actions. She described Frank's weird laughter and the apparent high that he got from inducing these emotional reactions. Teacher Assistant A believes that what finally stopped Frank from pursuing this behaviour was the shocked reaction of authority figures to what she describes as an act of severe cruelty by Frank. She believes that Frank did not want to risk disapproval by authority figures, who were important to him, but that he still did not understand how cruel and hurtful his behaviour was.

Others May Feel Hurt and Rejected by People With Asperger's

Although Teacher Assistant A has had several long term professional relationships with individuals with Asperger's syndrome, she has decided to stop working with this population. Part of her reason for leaving the autism-Asperger's field is the hurt and pain that she has felt when these individuals have severed ties with her for no apparent reason. Both Frank and David have abruptly ended their relationships with her despite hours of openness and giving on her part. She no longer feels able to give to a relationship with individuals with Asperger's, because they may cut off their relationship at any time and because she does not receive from them. Teacher

Assistant A explains the difficulty she has in attempting to maintain relationships with students such as Frank and David.

> *I don't trust their relationships with me. I guess I've given myself very freely to them, and I think it's their vulnerability that really gets to me. You know there is something in me that opens up to them and feels really comfortable with these students. Right away. I don't have to work at it. I'm not surprised at any of their reactions. Like I'm open to anything, any kind of reaction. And I'm not afraid of anger. I don't get shocked at some of the things they do. I can still get hurt because I haven't learned how to distance myself from the relationship. And I have formed relationships and I have been really hurt by Frank [sic] and David [sic]. Really hurt.*
>
> *And even though David [sic] is able to say maybe a word or two to me once in a while, when it's very, very quiet, and there's no one around, and he's in a good mood. It's only happened a couple of times. It makes a difference. But I'm always on the defensive now inside. I hold myself more distant, because I think it's an emotional disability. And I don't want to get hurt even though I tend to open up, and be vulnerable, and share things about myself that are personal with them. It's not that they've ever betrayed me, but it's the fact that I cannot receive. And if I can receive, like in a mutual sense, I can't trust that it might be cut off for no reason at all.*

I experienced the severing of ties that Teacher Assistant A is describing with David, as well. I had worked intensively, one-on-one with him for most of one term at school, after he refused to work with Teacher Assistant A. For the remainder of first term I attended class with him and tutored him on an individual basis. I spent most of each school day with him and for the

majority of the time we worked alone in a small, isolated study room. He did exhibit some unusual, bizarre behaviour, such as making loud sudden noises, imitating one of his teacher's for prolonged periods of time, and asking me what I would do when confronted with violent situations. However, for the most part he participated in study sessions and he seemed to appreciate my expertise.

Suddenly, at the beginning of second term his attitude toward me visibly changed. He no longer wanted me anywhere near him. In fact, if I attempted to move close enough to him so that we could both read the same piece of paper, he would viciously tell me to move away from him. I told Teacher A that it was as though he had suddenly decided that I smelled. By his body language and his harsh, angry tone of voice, he was showing that he was utterly rejecting me. His rejection was so blatant that it was ridiculous. At one point he purposely placed a walkman on the side of his face so that he could not see me as he passed me in the hall. Obviously, I could no longer work with him. I am puzzled as to why this sudden and utter rejection occurred.

Puzzling, unusual social behaviour by individual's with Asperger's syndrome is common. Strangers perceive this behaviour as willful, rude, and even deviant. Helping professionals and relatives may be profoundly hurt by it. Both acquaintances and people who have known individuals with Asperger's for years, may be unable to get past the barriers of socially inappropriate, bizarre behaviour to the person underneath. Whether the hurt and rejection comes from the individual with Asperger's or from the people in his/her community, the individual with Asperger's is in grave danger of being left alone and vulnerable to severe depression.

Abilities of Those with Asperger's May Compound Problems

Areas of Ability Hide Disabilities and Slow Diagnosis

Individuals with Asperger's are caught in another bind, which leads to negative outcomes for them. Initially, they present very well. They are often highly intelligent and extremely verbal, with areas of exceptional talent and aptitude. Their's is a subtle social disability. Teacher Assistant A said that it was difficult to describe Asperger's syndrome to her friends, and that she would tell them, *"The student that I am working with now, you can't really tell right away that he has a disability."* Asperger's syndrome may not be diagnosed until the child reaches Junior High School, or perhaps not at all. Both Martin and Jane, the children of Parent A and Parent B, were finally diagnosed as having Asperger's syndrome in Grade 7. Parent B believes that the late diagnosis has compounded her daughter's problems. She thinks that if she had known about Jane's disability when she was younger she would not have pushed her to perform in ways that she could not, and that she would have supported her in ways that would have enhanced her sense of self. Parent B expresses her regrets:

> *One of the things that I really regret about the lack of an early diagnosis is that I caused Jane [sic] a lot of needless suffering, because she shouldn't have had all of those corrections and all of those instructions. It was too much. It was too much for anybody. I mean you can't constantly be telling a child what's wrong with them. And that's what you're doing, in a sense, when you're giving them all those directions. And then expect them to feel good about themselves. You have to allow them some time to be themselves, you know, their autistic selves. Do you know?*
>
> *So that's the one thing that I regret. And I regret that about her teachers, too. I*

think that Jane [sic] has a lot of psychological problems, built on top of her Asperger's syndrome, because she has been pushed beyond what any person can be pushed and her self-concept has been eroded.

Areas of Ability Lead to Lack of Support and Over Expectations

Since they do not seem to have profound disabilities, children, adolescents, and adults with Asperger's syndrome are often left without the supports that they require. They are also frequently put in situations where they cannot cope because they do not have the social skills to do so. Over expectations, resulting in repeated failures, also feed into the downward spiral of crushed self-esteem and clinical depression. Teacher B emphasized how the appearance of ability may actually be a detriment to individuals with Asperger's syndrome.

I believe that the Asperger population is probably more needy that the more autistic population because they fool people. And they get into situations where they don't have the skills to cope. And yet the helping professionals feel that these individuals are capable and do have the necessary skill to sort of survive within the regular population.

Parents may also underemphasize the deficits of their children with Asperger's, putting them in untenable situations, according to Teacher B.

Many parents see them as being more capable than they actually are. Not so much that they don't see them as being Asperger's or they don't see them as having a disability, but they see them as being not as impaired as this other group. Therefore, they should be put on a pedestal. And unfortunately, they put them into a category that she or he is not capable of functioning within, and therefore, not always, but quite often, failure arises. And then all kinds of difficulties arise.

Individuals With Asperger's Able to Perceive Their Difference

Know Not Part of Mainstream or Profoundly Autistic Population

The capabilities of individuals with Asperger's, particularly their intelligence, may also lead to depression, because they can see that they do not have the clearly observable disabilities of the more autistic population, such as rocking and chanting, yet they know that they are not part of the mainstream. Parent B acknowledges that her daughter, Jane, knows that she is different. She says that she tries to encourage her daughter to accept herself as she is and that she tells Jane that she is a good, beautiful person. However, Jane replies, *"I hate this. I hate this. And I hate God for making me this way."*

Frustrated by Difference

Speech and Language Pathologist A believes that people with Asperger's syndrome are very intelligent and, therefore, very much aware that they are different. She states: *"And I think they get very frustrated with themselves and very angry with themselves."* Both Adolescent A and Adult A described the anger and frustration that they have felt in their lives. Adolescent A describes it as a tolerance problem. He says, *"I think I have a tolerance problem. I have a hard time tolerating stuff. I can get pretty nasty about things."* Adolescent A describes being very angry in Grade 3 and *"trashing"* the classroom, when his teacher treated him in a manner that he considered unfair and unjust. Frank, Jane, David, and Martin all become very angry and frustrated when they do not perform academically at the level of their peers.

Do Not Want to Be Categorized As Disabled

While they become very frustrated when they are not performing on a par with their peers, students with Asperger's syndrome may reject teacher or teacher aid support because they do not

want to be categorized as Disabled or Special Needs. Teacher Assistant A reported that Frank did not want to be seen as part of an Autism Program, and that he insisted that he attend class without the support of a teacher assistant. In my experience, this was certainly true of David, who did not want me sitting near him in class, talking to him while he was with his peers in the library, or walking with him in the hallway. In order to give him the intensive support that he needed to attend regular classes, I had to tutor him in an isolated, study room, where he could not be observed working with a teacher assistant. David also avoids entering the Autism room or attending any special events or fun occasions that involve other members of the Autism Program.

Disabilities Are Life-Limiting

Catch 22 Situation Increases Risks

Unfortunately, individuals with Asperger's syndrome do need intensive support to succeed in mainstream classrooms or in the workplace. When I asked Teacher B how he would describe life with adolescents with Asperger's to someone who has never experienced it, he replied:

> *Horrifying is one word that comes to mind simply because this is the population that is sort of in a Catch 22 position. They don't want to be stereotyped and they don't want to be clumped with individuals with more severe needs or severe handicaps, because they can visually see the difference between themselves and that population and they know that the regular population stigmatizes any kind of special grouping. And, of course, within our population the terms of "rubber room" and the "class of crazies" and things like that often come up.*
>
> *And then if you're an Asperger individual and you're in that situation, and yet*

you want to separate yourself from that situation and step out on you own, you're out there and dealing with other kids putting down some of your peers who are in the cluster group. And then also having to fend for yourself out there, where you don't have the skills. And quite often Asperger individuals, again, I use the term nerd, because they walk into situations that are so common place to regular students, and they don't know how to read a situation, and they become laughing stocks, and they becomes sort of, in some cases, the class clown.

Tragically, the subtle nature of the social disabilities of people with Asperger's syndrome may be life-limiting. Isolated areas of aptitude and an appearance of average or above average intelligence may prevent others from acknowledging the seriousness of their situation. They, themselves, may reject a label that categorizes them as disabled. They are truly caught in a Catch 22 situation that may lead to a lonely, friendless life, chronic unemployment, and acute depression. It is very difficult to find a way past the transparent bubble that encapsulates them. Because they have impaired social interaction skills, they have few, if any, meaningful social relationships. However, they have the desire to connect with others and the awareness to understand when they are being rejected and left alone. Since they do appear to be intelligent and capable, people overestimate their abilities and do not give them the supports that they require. At the same time, people with Asperger's syndrome may reject the support of professionals who work with the autistic population because they can see the differences between themselves and the more profoundly disabled members of the autistic population. Lack of support, repeated social failures, and over expectations by significant others, combined with an awareness of their difference from the mainstream population and a desire to belong, puts those with Asperger's

syndrome in a horrible situation. At times, it is life-threatening.

Teacher B expresses his concern about the seriousness of the Catch 22 position of those with Asperger's syndrome.

> *If people don't see the significance of the social deficit of individuals with Asperger's, it can be life-threatening. They are the individuals that are more likely to get left on their own, more likely to have undue pressure put on them because of those isolated skills that they have. People see the isolated skills and say, "But, oh, they're so talented and so gifted!" They don't see the capacity of the whole person.*

Teacher B has serious concerns about the future of David, the young man with Asperger's syndrome who rejected both Teacher Assistant A's and my support. Unfortunately, David presents a classic example of the impossible situation that many individuals with Asperger's find themselves in.

> *He's got so far to go, in a social context, that the future does not look very bright for this young man. The desire for social interaction is there, but he pushes aside any kind of helping had that is offered to get him through social situations.*
>
> *And he also has a family that sort of misrepresent his deficits in that area. They give him a false sense of security. They are also pushed aside when he wants to step out on his own. When one is as lacking in social insight as he is, you're just setting somebody up for failure. Again, you can't force somebody to try and learn.*

<u>Social Misunderstanding May Lead to Physical Danger</u>

As well as putting individuals with Asperger's at risk for academic, career, and social failure, the social deficits of the disorder place them in grave physical danger. Parents A and B

are worried about the physical safety of their children. Parent B describes a horrible choice for any parent.

> *The trials are safety. That's the worst trial of all. That's why she's not in the house. And why we couldn't have her live with us, because we couldn't keep her safe. We couldn't keep her from running out the door, running down the street. And also we wouldn't keep her from being violent in the house. Sometimes, we even have a hard time when she's visiting. She gets really angry and will throw things against the wall. Well, when she was in the hospital, she was threatening to kill herself and me with a knife. And threatening mainly to hurt herself. Mainly, it's threats against herself.*

Parent B is afraid her daughter may be sexually assaulted or physically beaten. She described several incidents where inappropriate social behaviour put her daughter in physical danger. In all of these incidents Parent B or her spouse felt that they had to intervene to protect their daughter. Each incident began as a common everyday occurrence that was escalated to the point of extreme danger by Jane's inappropriate social behaviour. Parent B describes one scenario:

> *She was in the park last summer. She thought these two big guys, on a bike, were looking at her funny. And so she stopped, and did some obscene gesture. And they were ready to haul off and hit her, you know. And my husband [sic] had to run up and do things to keep her safe.*

Routes to Meaningful Social Interaction Required

The horrific situation of those with Asperger's needs to be addressed. Parents, professionals, and community members should be aware of the seriousness of the social interaction disability of those with Asperger's. A way through the transparent bubble is required.

Routes to meaningful social interaction for those with Asperger's syndrome are essential, so that they are no longer isolated and in physical and psychological danger. These talented people should be active, contributing members of their communities. The purpose of this paper is to examine ways that adolescents with Asperger's syndrome may be included in social interaction plans, and thus drawn out of their isolating bubbles and into meaningful, life-enhancing relationships with members of their community.

BACKGROUND

Literature Review: Asperger's Syndrome

Historical Overview

Asperger's syndrome is a Pervasive Developmental Disorder which was first identified by Hans Asperger in 1944, when he labelled a group of children who were socially isolated and who displayed odd or eccentric behaviour as having "autistic psychopathy" (Szatmari, 1991, p. 81). Asperger's work gained little attention at the time since his research took place in Nazi Germany and a similar disorder had been described by the American, Leo Kanner, in 1943. Leo Kanner's work, describing a condition he called early infantile autism, became the basis of the world's understanding of the autism. The stereotypical picture of a child with Kanner's autism was that of a nonverbal, totally socially withdrawn child rocking in a corner. The actual term, "Asperger's syndrome" was first used by Lorna Wing (1981) as a descriptive diagnosis for those people with autism who did not fit the silent, aloof Kanner's stereotype (Happé, 1995, p.83). By the late 1980s researchers, Burd & Kerbeshian (1987), Gillberg & Gillberg (1989), Szatmari, Bremner, & Nagy (1989), and Tantam (1988), were beginning to list criteria for Asperger's syndrome (Happé, pp. 84-87). The translation of Hans Asperger's original dissertation into English by Uta Frith (1991), accompanied by her research and publications added to the understanding of Asperger's interpretation of autism. Finally, approximately fifty years after Asperger first described the disorder, Asperger's syndrome was listed as a distinct disorder in both the tenth revision of the International Classification of Diseases (ICD-10) of the World Health Organization (1992) and the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) of the American Psychiatric Association (1994).

Diagnosis and Differentiation of Asperger's Syndrome

Differentiation From Autism and Other Disorders

Since Asperger's syndrome has only recently gained attention, much of the research that has been conducted in this syndrome and the differentiation of Asperger's syndrome from autism, other Pervasive Developmental Disorders (PDDs), and other disorders. Prior to the 1994 publication of the DSM-IV, the closest description to Asperger's syndrome in the Diagnostic and Statistical Manual of Mental Disorders would have been the category Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The diagnosis pervasive developmental disorder (PDD) is a broad classification for individuals who present with a triad of impairments, including "reciprocal social interaction, verbal and nonverbal communication, and restricted range of imaginative activities" (Szatmari, 1991, p 82). Autism is considered a subgroup within the PDD spectrum and the diagnosis PDD-NOS was given to people who did not meet all of the criteria for autism, including people who would be diagnosed as having Asperger's syndrome today. Presently, there is still considerable debate about whether Asperger's syndrome should be considered a distinct developmental disability within the PDD spectrum or a form of higher functioning autism.

As well as being confused with other forms of PDD, Asperger's syndrome has also been misdiagnosed as: Obsessive-Compulsive Disorder, General Anxiety Disorder, Schizoid Personality Disorder, Childhood Schizophrenia, Attention Deficit Disorder, Mental Retardation, Developmental Language Disorder, Sematic-Pragmatic Disorder, or Learning Disability. In a study by Fine, Bartolucci, Ginsberg, and Szatmari (1991) the researchers discovered that previous diagnoses for their group of 28 subjects with Asperger's Syndrome included:

"hyperactivity, anxiety disorder, learning disability, elective mutism, borderline schizophrenia, obsessive-compulsive disorder, and adjustment reaction" (p. 774). Since Asperger's syndrome is a subtle disability, diagnosis and differentiation from other disorders continues to be problematic.

Differentiation of Asperger's Syndrome From Kanner's Autism

Areas of Agreement Between Asperger and Kanner

Differentiation of Asperger's autism from Kanner's autism has been the focus of much of the research in this area. There are a number of remarkable similarities and coincidences in the research of these two men, leading to the conclusion by some researchers (Frith, 1991; Volkmar, Paul, & Cohen, 1985) that Kanner and Asperger were describing the same disorder and by other researchers (Gillberg & Gillberg, 1989; Szatmari, 1991; Tantam, 1991; Wing, 1981, 1991) that they were describing subgroups within an autistic continuum. The term autistic was first coined by Bleuler (1908), who used the word (from the Greek "autos" meaning "self") to describe the social withdrawal seen in adults with schizophrenia (Happé, 1995, p. 11). Working independently, both Asperger and Kanner chose to use the word autistic to label the population they were studying. They also both regarded the social handicap of people with autism to be pervasive, with Kanner (1943) calling it "innate" and Asperger (1944) saying it was "constitutional" (Happé, p. 11). Poor eye contact, stereotypes of word and movement, marked resistance to change, isolated special interests, and an attractive appearance all appeared in the diagnostic description of the autistic disorder that both men were investigating (Happé, p. 11). They also both differentiated autism from schizophrenia by saying that their clients with autism did not hallucinate, appeared abnormal from their earliest years, and showed improvement rather than deterioration (Happé, p. 11). Interestingly, Asperger and Kanner shared the observation that

the parents of their autistic clients often showed similar autistic traits, such as "social withdrawal or incompetence, obsessive delight in routine, and the pursuit of special interests to the exclusion of all else" (Happé, p.11).

Areas of Disagreement Between Asperger and Kanner

Despite the significant similarities in their diagnostic descriptions, Asperger and Kanner also appeared to disagree in three crucial areas of diagnosis, providing the opportunity for other researchers (Van Krevelen, 1971) to conclude that they were describing distinct disorders (Happé, 1995, p. 92). The quality and the timing of the development of language in autistic children proved to be the most controversial diagnostic area. In their initial papers Kanner emphasized the absence of language in his patients, while Asperger drew attention to the amazing vocabulary of some of his subjects. Three of Kanner's eleven patients never spoke and he concluded that the others were not actually using language to communicate. Kanner (1943) stated, "In none . . . has language . . . served to convey meaning" (Happé, 1995, p. 12) and he used examples of "echolalia, pronoun reversal, and difficulties in generalizing word meanings" (Frith, 1991, p. 10) to show the meaningless of the language that was used. All four of the patients Asperger described in his dissertation spoke fluently, with Asperger (1944) describing the six to nine-year-old as speaking "like little adults" (Happé, p.12) and remarking on their clever-sounding language, with its advanced vocabulary and invented words. Asperger (1944/1991) said of his subjects: "They are able to express their own original experience in a linguistically original form. This seen in the choice of unusual words which one would suppose to be totally outside the sphere of these children" (pp. 70-71).

Although Asperger commented on the unusual, and often early development of

vocabulary of his subjects, he also noted the abnormalities that occurred in the language of children with autistic psychopathy, stating that language usage was a useful means of diagnosis. He described peculiarities in the language of his subjects such as:

> Sometimes the voice is soft and far away, sometimes it sounds refined and nasal, but sometimes it is too shrill and earsplitting. In yet other cases, the voice drones on in a sing-song and does not even go down at the end of a sentence. Sometimes speech is over-modulated and sounds like exaggerated verse-speaking. However many possibilities there are, they all have one thing in common: the language feels unnatural, often like a caricature, which provokes ridicule in the naive listener. (Asperger, 1944/1991, p. 70)

In a footnote in her translation of Asperger's dissertation Frith (1991) explains that "Asperger's descriptive phrase "talking like an adult" suggests oddness over and above precocity" (p. 39). Wing (1981) also points out the oddness of the speech of children with Asperger's syndrome, describing it as grammatically perfect, but with an abnormal, pedantic content, often consisting of lengthy speeches about a favourite subject (Happé, 1995, p. 116).

In addition to peculiarities in the verbal component of speech of his subjects, Asperger noted an oddness in the non-verbal aspects of communication. Although all of his subjects spoke fluently, he noted abnormalities in their communication, especially in the use of gaze to establish non-verbal contact in a conversation. He observed an abnormality of gaze, so that "hardly ever does their glance fix brightly on a particular object as a sign of lively attention and contact" (Asperger, 1944/1991, p. 68) and commented that this peculiarity in eye contact was particularly evident when they were in conversation with others.

> Glance does not meet glance as it does when unity of conversational contact is

> established. When we talk to someone, we do not only 'answer' with words, but we 'answer' with our look, our tone of voice, and the whole expressive play of face and hands. A large part of social relationships is conducted through eye gaze, but such relationships are of no interest to the autistic child. (p. 69)

Considering the oddness that Asperger described in the use of language and non-verbal aspects of communication, one could argue that there is agreement between Asperger and Kanner in the language realm, since both are describing profound difficulties in communication. However, many people have understood Kanner as describing a complete lack of language and Asperger as describing a precocious, odd use of language.

Secondly, Asperger and Kanner disagreed about the motor skills of their subjects. Kanner (1943) noted the manual dexterity that his subjects used to spin objects and to find success on the Seguin form board and concluded that they were capable of "excellent, purposeful and intelligent relations to objects" (Happé, 1995, p. 12). Conversely, Asperger (1944) reported both clumsy, poor gross motor coordination and problems with fine motor skills, such as writing, in his subjects, concluding that "the essential abnormality in autism is a disturbance of the lively relationship with the whole environment" (Happé, p. 12).

Finally, Asperger and Kanner disagreed on the learning style of their subjects, with Kanner promoting rote learning as the preferred style of his subjects and Asperger (1944) endorsing the use of the child's own learning system ("best when the child can produce spontaneously") and suggesting that they are "abstract thinkers" (Happé, p. 12). Asperger seemed to be influenced by his subjects' original language, their stubborn insistence on following their own interests, and their unusual methods in intellectual problem-solving when he advocated

letting autistic children follow their own learning systems. Indeed, he remarked on the difficulty that was encountered when someone tried to teach a child with autistic psychopathy, saying that: "They are simply not set to assimilate and learn an adult's knowledge" (Asperger, 1944/1991, p. 70). Although he noted the rote learning abilities of his subjects, Asperger was most impressed with what he described as their original thought and he emphasized "rich, original language production" such as: "'My sleep today was long but thin.' or 'I can't do this orally, only headily.' or 'I don't like the blinding sun, nor the dark, but best I like the mottled shadow.'" (p. 71), to prove their intellectual capabilities. Thus, the impression was given that Asperger was studying a population that was capable of intellectual originality, while Kanner was describing a group that required rote learning.

Both Kanner and Asperger, like most researchers who have studied autism, used their clinical experiences with this population to develop diagnostic criteria for the disorder. Over time, the emphasis of their diagnostic criteria changed. Kanner's first paper highlighted the following features as important aspects of autism:

1. extreme autistic aloneness
2. anxiously obsessive desire for the preservation of sameness
3. excellent rote memory
4. delayed echolalia
5. over sensitivity to stimuli
6. limitation in the variety of spontaneous activity
7. good cognitive potentialities
8. highly intelligent families (Happé, 1995, p. 10)

Later, Kanner decided that "extreme isolation and the obsessive insistence on the preservation of sameness" (Kanner & Eisenberg 1956) were the key elements of autism and that the other features that he had listed earlier were either secondary to or caused by these two core conditions (Happé, p. 10). Kanner's emphasis on aloneness formed the basis of the world's understanding of autism. Autistic children were seen as beautiful, intelligent children tragically locked in silence from the world.

Asperger's concept of autistic psychopathy in children also changed subtly, over time. When he first described autism, Asperger used case studies and his descriptions and analysis of these case studies to present autistic psychopathy to the world. He did not present a short, concise list of criteria that people could easily use to identify autism. His interest and emphasis at the time of his dissertation influenced the content of his paper and also subsequent interpretations of his work. For example, Asperger (1944/1991) stated that autism could occur in children of all intellectual ranges: "The autistic personality is certainly not only found in the intellectually able. It also occurs in the less able, even in children with severe mental retardation" (pp. 58-59). However, the emphasis in his paper on originality of thought in children with autistic psychopathy, obscured his statement about autism in Mentally Retarded children. He seemed to be particularly interested in those who were intellectually gifted, and this interest showed in the direction of his dissertation. Frith (1991) explains in a footnote, "The important insight that autism can occur at all levels of intellectual ability, including the subnormal range of intelligence, has often been overlooked, even by Asperger himself in his later papers" (p. 59). Asperger's emphasis and interest in an individual with autism with higher intellectual abilities and readers' interpretations of that emphasis have lead to the current

stereotypical image of people with Asperger's syndrome as being: "socially inept but often socially interested, articulate yet strangely ineloquent, gauche and impractical, and specialists in unusual fields" (Frith, pp. 11-12).

Reintroduction of Asperger's Syndrome

Active But Odd and Asperger's Description of Autism

Asperger's interpretation of autism did not become known to the world for many years after Kanner's description of aloof, silent children became the prototype for autism. However, clinicians such as Lorna Wing were encountering individuals with autism who did not fit into the stereotypical, isolated, model of Kanner's autism. Initially, Wing developed a subclassification for autism to account for the variation in the autistic population. Her subclassification was based on the degree of social withdrawal that was displayed by the individuals with autism and included three subtypes within the autistic spectrum: "aloof", "passive", and "active but odd". Those in the aloof group would best fit Kanner's description of autism, those in the "active but odd" group were more typical of Asperger's description of autism, and those in the passive group had elements of both descriptions. Later, wanting recognition for these "more able" individuals in the "passive" and "active but odd groups", Wing (1981) was the first to use the label "Asperger's syndrome" to identify this verbal, extremely socially odd population. Wing listed six diagnostic criteria for Asperger's syndrome based on her interpretation of Asperger's 1944 description:

1. Speech-no delay, difficulty using pronouns correctly, content odd, pedantic, often lengthy oratory about favourite subject
2. Nonverbal communication-little facial expression, monotone voice, inappropriate

gesture, poor comprehension of others expressions and gestures

3. Social interactions-lack of ability to understand and use the rules governing social behaviour, naive and peculiar social behaviour

4. Resistance to change-often enjoy spinning objects, intensely attached to particular possessions, unhappy away from familiar places

5. Motor coordination-gait and posture odd, gross movements clumsy, poor at games involving motor skills, sometimes poor fine motor, such as in writing or drawing

6. Skills and interests-excellent rote memory, intensely interested in one or two subjects, absorb facts about subject but have little grasp of the meaning of the facts (pp. 116-117)

Modifications to the Diagnostic Criteria for Asperger's Syndrome

Wing modified the description of Asperger's autism that she had extracted from Asperger's dissertation, making three changes which reflected the knowledge she had gained from interviewing parents about the developmental history of the clients she had identified as having Asperger's syndrome. Although only one of the four children described in his dissertation talked before he walked, Asperger emphasized that his subjects spoke before they walked and that their linguistic skills were "highly sophisticated." Wing (1981) discovered a variety of early developmental discrepancies between the reported histories of 34 of her clients with Asperger's syndrome and Asperger's account (p. 117). Wing explains the discrepancies between her cases and Asperger's account of language and early development:

> Slightly less than half of the present author's more typical cases of Asperger's syndrome were walking at the usual age, but were slow to talk. Half talked normally but were slow to walk, and one both walked and talked at the expected times. Despite the eventual good

> use of grammar and a large vocabulary, careful observation over a long enough period of time discloses that the content of speech is impoverished and much of it is copied inappropriately from other people or books. The language used gives the impression of being learned by rote. The meanings of long and obscure words may be known, but not those of words used every day. (p. 117)

Secondly, Wing (1981) found evidence that the parents of her clients with Asperger's syndrome had noticed an unusual lack of social responsiveness in their children at a very early age. Asperger (1944/1991) had reported that the symptoms of autism are present from the second year of life: "From the second year of life we find already the characteristic features which remain unmistakable and constant throughout the whole life-span" (p. 67). However, many people had the impression that early detection of Asperger's syndrome was very difficult. Frith (1991) states in a footnote to Asperger's comment about finding autistic features in two-year-olds: "This important statement, that symptoms are present from the second year of life, is so well buried in the text that it has often been overlooked. Instead the belief has persisted that Asperger's cases show normal development, especially in language, up to three years, or later" (p. 67). Wing found that during careful interviewing the parents of her clients reported such autistic features in their babies and toddlers as: "limited babbling, no sharing of toys or interesting events in the environment with parents or visitors, and a general lack of the intense urge to communicate in babble, gesture, movement, smiles, laughter, and eventually speech that characterizes the normal baby and toddler" (p. 117).

Finally, Wing (1981) disagreed with Asperger's belief that individuals with Asperger's syndrome are capable of "originality and creativity in their chosen field" (p. 118). Instead Wing

believes that their thought process is extremely linear, with the appearance of exceptional cognitive abilities being inaccurately perceived because of their unusual approach to intellectual problem-solving. Wing presents her argument:

> It would be more true to say that their thought processes are confined to a narrow, pedantic, literal, but logical, chain of reasoning. The unusual quality of their approach arises from the tendency to select, as the starting point for the logical chain, some aspect of a subject that would be unlikely to occur to a normal person who has absorbed the attitudes current in his culture. Usually the result is inappropriate, but once in a while it gives new insight into a problem. (p. 118)

Wing's descriptive reintroduction of Asperger's type autism, accompanied by her own clinical observations, gained attention and provided a basis for the identification of this form of autism. However, the syndrome, as Wing described it, was broader than the prototype of clever-sounding, verbally precocious, socially odd children that many people have interpreted Asperger as describing. By de-emphasizing the clumsy, motor impairments and modifying the description of language and early development, Wing was perhaps including individuals with a form of higher functioning, Kanner's-type autism in her diagnostic category. On the other hand, she may have been including individuals that should have been considered in the Asperger's category. Whether Wing's 1981 description was accurate or not, it was the primary basis for future descriptions of Asperger's syndrome and for clinical diagnosis of Asperger's syndrome.

Criteria for Asperger's Syndrome Established

Similar Profile Develops

By the end of the 1980s, a number of researchers were listing diagnostic criteria for

Asperger's syndrome, based on Wing's 1981 description of Asperger's autism, and a similar profile was beginning to develop. Burd and Kerbeshian (1987) gave five features as a description of Asperger's syndrome:

1. speech-pedantic, stereotyped, aprosodic
2. impaired nonverbal communication
3. social interaction-peculiar, lacks empathy
4. circumscribed interests-repetitive activities or savant skills
5. movements-clumsy or stereotyped (Happé, 1995, p. 84-85)

Tantam (1988) in his studies of adults with Asperger's syndrome recognized the same five core features (Happé, p. 85). Gillberg and Gillberg (1989) have given a detailed list of six criteria that they have found useful in diagnosing Asperger's syndrome (Appendix A). Gillberg and Gillberg's list contains the same five key features as that of Burd, Kerbeshian, and Tantam, with the addition of the criterion describing how routine is imposed on all aspects of their lives: "A stereotyped way of trying to introduce and impose routines or the particular interest in all or almost all aspects of ordinary life" (Gillberg & Gillberg, 1989, p.632). Similarly, Szatmari, Bremner, and Nagy (1989) proposed a list of criteria to help identify Asperger's syndrome that included the descriptors: "solitary, impaired social interaction, impaired nonverbal communication, odd speech, and does not meet DSM-III-R criteria for Autistic Disorder" (p. 558) (Appendix B). Although the diagnostic criteria among the researchers differs slightly, each list contains a description of unusual, odd speech and a difficulty with social interaction. The question remains whether these criteria are enough to differentiate Asperger's syndrome as a distinct disability.

Asperger's Original Dissertation Translated

Uta Frith provided clinicians with an English translation of Asperger's original dissertation and her interpretations of his work in 1991. Frith's careful study of Asperger's work and her own clinical practice have lead her to conclude that Asperger and Kanner were describing the same type of disabled child (Frith, 1991, p. 6). She speculates that perhaps the slight differences in their accounts of autism were due to the population that each of them were studying, suggesting that, "the possibility that the prototype Kanner had in mind was younger--with delayed and markedly deviant language acquisition--was, in short, a child with a more blatant and severe communication disorder" (p. 11). Frith presents superior language abilities as the prime diagnostic tool for identifying individuals with Asperger's syndrome-type autism. She says that "they tend to speak fluently by the time they are five, even if their language development was slow to begin with, and even if their language is noticeably off in its use for communication" (p. 3). She acknowledges that using language ability as the prime diagnostic tool may lead to a change in diagnosis for certain individuals, who present as profoundly autistic in early childhood, but who begin to use language fluently as they mature. Frith suggests that Asperger was describing a variant of autism and that his case descriptions should be used in the overall understanding of autism.

Social Interaction Deficit Criterion Key

Asperger (1994/1991) introduces his dissertation on autistic psychopathy by stating that "This disturbance results in severe and characteristic difficulties of social integration. In many cases the social problems are so profound that they overshadow everything else" (p. 37). He then goes on to describe four boys who are unable to relate to their parents, play with their peers, or

follow the social rules in school. Asperger describes autism as a "disturbance of lively relationship with the whole environment" (p. 74) which disallows normal interaction with people and objects throughout the afflicted individual's life-time. Asperger says that although the problems that occur may change as the individual matures, they are all based on a fundamental inability to relate to the environment. This inability to relate to the environment is manifested by the following problems at different stages of development: "In early childhood there are the difficulties in learning simple practical skills and in social adaption. These difficulties arise out of the same disturbance which at school age cause learning and conduct problems, in adolescence job and performance problems, and in adulthood social and marital conflicts" (p. 68). Asperger states that "the nature of these children is revealed most clearly in their behaviour towards other people" (p. 77). He then goes on to describe how the highly verbal children who he was describing were unable to successfully interact with others and were not able to understand others' feelings or learn by intuition.

> With uncanny certainty, the children manage to do whatever is the most unpleasant or hurtful in a particular situation. However, since their emotionality is poorly developed, they cannot sense how much they hurt others, either physically, as in the case of younger siblings, or mentally, as in the case of parents. . . . They can lean only with the help of elaborate rules and laws and are unable to pick up all those things that other children acquire naturally in unconscious imitation of adults. (p. 77)

Clearly, Asperger was describing social interaction as the prime deficit of autism and also that abnormalities in social interaction could be used as a key diagnostic tool.

Description of Social Interaction Deficit of Asperger's

Clinicians have used the extremely unusual, odd, and totally inappropriate social interaction of individuals with Asperger's syndrome to identify the disorder and to differentiate it from autism. They differentiate individuals with autism and Asperger's syndrome by perceiving those with autism as not wanting to relate to others and those with Asperger's as not knowing how to relate to others. The unusual approaches to social interaction that individuals with Asperger's may display form part of a clinician's criteria for the diagnosis of Asperger's syndrome. This social interaction difficulty is especially evident in attempted interactions with childhood peers. Clinicians have noticed that it is in the area of reciprocal interaction with their peers that children with Asperger's encounter the most difficulty and show the most impairment. A child with Asperger's syndrome may be able to relate to an adult in an one-on-one situation, where the focus is on the child and his or her interests. This may be because an adult may compensate to allow for idiosyncrasies of the child's conversation. However, as soon as more people are introduced to the situation or the focus changes to the adults' world, the social impairments of Asperger's become evident. It appears that the child with Asperger's syndrome has great difficulty with modifying his or her social behaviour to the demands of the environment. Szatmari (1991) says that they are always "out of context" (p. 82).

Although the child with Asperger's may be extremely articulate and have a large vocabulary, there appears to be something not quite right in his or her attempts to communicate. Szatmari (1991) explains this impairment in communication by stating that a child with Asperger's experiences: "a profound difficulty in the pragmatics of social communication, that is in the creation of social meaning through communication" (p. 82). Wing (1981) describes the

impairment of two-way social interaction:

> The problem arises from a lack of ability to understand and use the rules governing social behaviour. These rules are unwritten and unstated, complex, constantly changing, and effect speech, gesture, posture, movement, eye contact, choice of clothing, proximity to other, and many other aspects of behaviour. Their social behaviour is naive and peculiar. They do not have the intuitive knowledge of how to adapt their approaches and responses to fit in with the needs and personalities of others. (p. 116)

According to Szatmari, some of the behaviours that indicate that a child with Asperger's is having difficulty with the pragmatics of social communication are:

> 1. extreme difficulty in initiating and sustaining a conversation
>
> 2. a use of language as a means to a particular concrete end
>
> 3. speech often characterized by a lack of inflection or by unusual placement of inflection in a sentence
>
> 4. conversation that is often: tangential, off the point, or circumstantial
>
> 5. conversation that lacks cohesion and provides few links among thoughts
>
> 6. an inability to use social context to provide appropriate and useful information to the listener (p. 83)

These behaviours provide the observer with an impression that something is not quite right in the conversation of the child with Asperger's. Language is being used and conversation is taking place, but somehow full communication is not taking place. This lack of reciprocal conversation and communication becomes especially evident in situations where communication with peers is attempted and the peer expects the give and take of a normal conversation to take

place. When a child with Asperger's fails to use language to communicate in a reciprocal fashion, he or she has a great deal of difficulty with establishing social interactions and even minimal peer relationships. This social interaction deficit becomes particularly painful at adolescence, when there is a strong need to interact with one's peers.

Research Evidence Linking Asperger's Syndrome and Autism

Improvement With Maturation

Some researchers (Gillberg & Gillberg, 1989; Szatmari, 1991; Tantam, 1991; Wing 1981, 1991) identify Asperger's syndrome as a subtle form of autism, with reciprocal social interactions with peers providing the most difficulty. The degree of social aloofness seems to improve in some individuals with autism as they mature. Wing (1981) reported that some of the children that she classified as being "aloof" as young children attempted to interact with others as they became older, so that she would reclassify them as "active but odd." Other researchers (Gillberg, 1991; Gillberg & Steffenburg, 1987; Wing, 1981, 1988) have reported children diagnosed in early childhood with autism, who were later diagnosed as having Asperger's syndrome (Ozonoff, Rogers, & Pennington, 1991, p. 1117). This change in diagnosis seems to indicate that change and growth is possible in those with autism and that experience and maturation may lead to fewer symptoms of Kanner's type autism and thus the diagnosis of Asperger's syndrome. However, if it is possible for those with Kanner's autism to become less aloof as they mature and to become more like the Asperger's population, it would seem that Kanner's autism and Asperger's syndrome are two manifestations of the same disorder and that the differences reported between them may be differences in maturation and development. Frith's (1991) assertion that Asperger and Kanner were describing the same disorder would be

correct. This would seem to indicate that those with Asperger's are less autistic, less removed from the world than those with Kanner's autism, because they have learned ways to begin to approach others. If this is true Asperger's syndrome should be considered a description of the high end of an autistic continuum.

Co-occurence in Families

Adding to the evidence that Asperger's syndrome and Kanner's autism may be the different degrees of autistic severity and different manifestations of the same disorder are the family studies which have identified the co-occurrence of Asperger's syndrome and autism. Bowman (1988) studied a family where four sons and their father all displayed a variety of PDD symptoms from mild Asperger's like traits, to Asperger's syndrome, to severe Kanner-type autism, where the child was thought to be retarded before the age of 30 months (p. 380). Burgaine and Wing (1983) noted triplets whose autism ranged from Asperger's type to Kanner-type. Eisenberg (1957), like both Kanner and Asperger, noted the autistic-like traits in the parents of his clients, reporting that children with autism had Asperger's syndrome-like fathers (Happé, 1995, p. 91). DeLong and Dwyer (1988) studied 929 1st and 2nd degree relatives of children with autism and discovered a high incidence of Asperger's syndrome in families of autistic children with IQs of greater than 70, but not in the families of more intellectually handicapped children (Happé, p. 91). Finally, Gillberg (1991) presented six family studies that showed people with autism, Asperger's syndrome, and Asperger's-like traits in the same family.

Research Differentiating Asperger's Syndrome and Autism

Researchers have attempted the difficult task of differentiating Kanner's autism and Asperger's syndrome in individuals who are high-functioning. According to Klin, Volkmar,

Sparrow, Cicchetti, and Rourke (1995) Asperger's syndrome has been inconsistently identified by clinicians, "some of whom have employed it to refer to autistic persons with higher levels of intelligence, adults with autism, or even as a broader term for all "atypical" children who do not fulfill criteria for autism" (p. 1128). Part of the difficulty of diagnosis is in defining the term "high-functioning." If high-functioning is considering being able to approach others and being less socially aloof, the social interaction criterion can be used to differentiate the two disorders and everyone who was identified as being "high-functioning" would also be identified as having Asperger's syndrome. Asperger's syndrome would become a "catch all" diagnostic category that would include individuals who because of maturation, learning, or individuality do not meet the criteria for autism.

However, the generally accepted definition of high-functioning autism (HFA) is "autism associated with overall normal intelligence" (Klin et al., 1995, p. 1128). Szatmari and Jones (1991) reviewed the research on IQ and genetics and concluded the "the IQ of an autistic child does not index severity of autism" (Happé, 1995, p. 88). This would seem to indicate that there are highly intelligent individuals with Kanner's type autism, who are extremely autistic and aloof, and that there are individuals with low intelligence, who are mildly autistic, "active but odd", with an Asperger's type disorder. Although Kanner's autism has been associated with low intelligence and social withdrawal and Asperger's syndrome has been associated with high intelligence and bizarre social approach, both men believed that the autistic disorder that they described could occur at either end of the intelligence range. Kanner remarked on the intelligence potential of his subjects (Happé, 1995, p. 10) and Asperger insisted that the pattern of impairments that he described could occur in children of low intelligence (Happé, p. 85;

Asperger, 1944/1991, pp. 58-59).

Researchers have begun to compare individuals who have been given the high-functioning autistic (HFA) label and those who have been labelled Asperger's to determine if they can be differentiated. There are conflicting results from this research. Some researchers (Ozonoff, Rogers, and Pennington, 1991) believe that they can differentiate HFA and Asperger's, while others (Ghaziuddin, Butler, Tsai, & Ghaziuddin, 1994) conclude that there is not sufficient evidence to differentiate the two disorders. Part of the problem with this research is how the subjects of the research were given the diagnostic label of Asperger's or HFA initially. Researchers (Wing, 1991) have found that they can change the diagnosis of their subjects from HFA to Asperger's or Asperger's to HFA by changing the diagnostic criteria that is used. Thus, some of the research designed to differentiate Asperger's and HFA appears to be rather circular and inconclusive.

Attempts to differentiate Asperger's and HFA have focused on the differences in the clinical criteria for diagnosis of the two disorders. For example, although Ghaziuddin et al. (1994) did not find significant differences between their subjects with Asperger's and their subjects with HFA, they used the repeated clinical accounts of clumsiness in individuals with Asperger's as the basis for their research. Clinically, some professionals perceive right brain deficits in those with Asperger's and left brain deficits in those with autism. They point to the language strengths and the motor clumsiness of those with Asperger's and the language weakness and motor strengths of those with autism as proof of this hemispheric difference. Some researchers (Volkmar et al., 1994), who have used the Weschler Intelligence Scale for Children (WISC) and Weschler Adult Intelligence Scale (WAIS) (Weschler, 1994, 1981) as tools

to analyze the differences between HFA and Asperger's, believe that those with Asperger's show a higher Verbal versus Performance score, while those autism show a higher Performance versus Verbal score (Klin et al., 1995, p. 1129). Ozonoff, Rogers, and Pennington (1991) concluded that those with HFA and Asperger's can be differentiated. The results of their study seem to indicate a left brain strength for their subjects with Asperger's and a right brain strength for their subjects with HFA, with only the high-functioning autistic group showing deficiencies in theory of mind and verbal memory, and only the Asperger's syndrome group showing deficiencies in emotional perception (p. 1115). Other researchers (Van Krevelen, 1971) have noted that their subjects could be differentiated on the basis of language abilities, motor coordination, and degree of social interaction, and concluded that Asperger was describing a separate disorder (Happé, 1995, p. 92).

Despite inconclusive research results in the attempt to differentiate HFA and Asperger's, practising clinicians tend to use the indications of right brain deficits and left brain strengths, such as the motor delays and clumsiness and advanced speech described by Asperger, to differentiate Asperger's syndrome from higher-functioning autism. For example, Atlas and Gerbino-Rosen (1995) used their client's history of "age-appropriate language skills and cognition, motor clumsiness, and yearning to relate to others" (p. 208) to diagnose Asperger's syndrome, despite an early history of features which might suggest Autistic Disorder, such as "touch avoidance, gaze aversion, and perseverativeness" (p. 207). Others (Klin et al., 1995; Pope, 1993) have pointed to the similarities between Asperger's and disorders which indicate right brain disfunction, such a semantic-pragmatic disorder and non-verbal learning disability, as an indication that Asperger's might have a right brain causality.

Prevalence and Etiology of Asperger's Syndrome

Prevalence

Since a variety of diagnostic criteria for Asperger's syndrome have been used to identify people with Asperger's syndrome, the prevalence figures for the disorder vary. Using the six criteria for Asperger's syndrome that they had developed, Gillberg and Gillberg (1989) found a prevalence rate of 10-26 per 10,000 among children of normal intelligence, another .4 per 10,000 among children with mild mental retardation, and zero among children with more severe mental retardation. In a subsequent study involving a screening of 1519 Swedish school children, Ehers and Gillberg (1993) found a prevalence of 0.36% using the Gillberg and Gillberg criteria (Appendix A), 0.50% using Szatmari, Bremner, and Nagy (1989) (Appendix B) criteria, and 0.29% using strict ICD-10 (1992) criteria (Appendix C) (p. 1340).

Asperger's (1944) subjects were all male and he thought that the autistic disorder which he was describing would be much more common in males, speculating that "autistic psychopathy might be an extreme variant of male intelligence", which he believed was more abstract and logical than that of females (Wolff & McGuire, 1995, p. 795). Males have been more frequently identified as having Asperger's syndrome than females, with Ehers and Gillberg (1993) finding a male to female ratio of 4:1, using Gillbergs' criteria.

Etiology

The exact nature of the etiology of Asperger's is unknown. Szatmari (1991) states that: "Like other PDDs, Asperger's syndrome has a developmental-neurologic etiology" (p. 87) and that: "Presumably, areas of the brain responsible for socialization, communication, and play have been disrupted in some functional or microstructural manner" (p. 87). The examples of autism

and Asperger's syndrome being found in the same family (Bowman, 1988; Gillberg, 1991; Wing, 1991) suggest that there is a common genetic etiology for the two disorders. Van Krevelen (1971) suggested that "autism results when there is the genetic predisposition for Asperger's syndrome plus the occurrence of brain damage" (Happé, 1995, p. 92). Others (Klin et al., 1995; Pope, 1993) have suggested a right-brain defect in Asperger's syndrome, as opposed to disfunction in the left brain for those with autism. Prevalence studies have found that Asperger's is more common than autism, occurring in at least the 26-29 per 10,000 range (Ehers & Gillberg, 1993; Gillberg & Gillberg, 1989) compared to 2.0-4.5 per 10,000 for autism (Gillberg & Gillberg, 1989). Of course this comparison also depends on the criteria for autism and for Asperger's syndrome being used in the survey.

Categorization in DSM-IV

Categorization and Description in the DSM-IV

Whether Asperger's syndrome is part of the autistic continuum or a separate developmental disability, it was listed as one of five Pervasive Developmental Disorders in the DSM-IV. The other disorders in this category are: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism) (American Psychiatric Association, 1994, pp. 65-78). The DSM-IV lists similar criteria to those given by Wing (1981), Gillberg and Gillberg (1989), and Szatmari, Bremner, and Nagy (1989) except in the area of language, where the DSM-IV does not note the difficulties in language that the researchers have reported, stating instead that there is "no clinically significant general delay in language" (American Psychiatric Association, 1994, p. 77). Like the DSM-IV, the ICD-10 fails to emphasize the subtle difficulties with language that those

with Asperger's seem to experience, stating instead: "A lack of any clinically significant general delay in language or cognitive development. Diagnosis requires that single words should have developed by two years of age or earlier and that communicative phrases be used by three years of age or earlier" (World Health Organization, 1992). The following diagnostic criteria for Asperger's syndrome are listed in the DSM-IV:

1. Qualitative impairment in social interaction

2. Restricted repetitive and stereotyped patterns of behaviour, interest, and activities

3. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

4. There is no clinically significant general delay in language.

5. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour, and curiosity about the environment in childhood.

6. Criteria are not met for another specific Developmental Disorder or Schizophrenia.

(American Psychiatric Association, 1994, p. 77)

Differentiation From Autism in the DSM-IV

The DSM-IV diagnostic criteria for Autistic Disorder differs from the above criteria for Asperger's Disorder in that "qualitative impairments in communication" (p. 70) is listed as a criterion for autism and not mentioned for Asperger's syndrome. Also, the Autistic Disorder criteria include: "Delays or abnormal functioning in at least one of the following areas, with onset prior to age three years: (a) social interaction, (b) language as used in social communication, or (c) symbolic or imaginative play" (p. 71), whereas the criteria for Asperger's

Disorder state: "There is no clinically significant delay in language, cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour, and curiosity about the environment in childhood" (p. 77).

It appears from these diagnostic criteria that the DSM-IV is indicating that Asperger's syndrome causes a subtle impairment of social interaction and that it may be differentiated from autism by the quality of the impairments that are manifested. It seems from the DSM-IV descriptions of Asperger's and autism that Asperger's is considered a less severe manifestation of autism and that it might be placed at the top end of an autistic continuum. Although Asperger's syndrome is listed as a separate disorder in the DSM-IV, the DSM-IV criteria for Asperger's syndrome do not seem to differentiate Asperger's from autism in such a way to make Asperger's the unique disorder that Hans Asperger described.

Research Investigating the Social Interaction Deficit of Asperger's

Overview of Social Interaction Research

Researchers have recognized that social interaction is one of the prime deficits of both Asperger's syndrome and autism. It seems to be the prevalent deficit of those with Asperger's syndrome and it is also seems to exist on a continuum within the autistic spectrum of disorders. Research in the area of social interaction has provided some data that differentiates Asperger's and autism and that also provides a basis for theories that attempt to explain the two disorders.

Researchers have begun to examine why it is difficult for people with Asperger's and autism to communicate with others. Research has ranged from an examination of the gaze response of those with Asperger's to studies that have tested whether those with autism and Asperger's have a "theory of mind." Tantam, Holmes, and Cordess (1993) theorized from their

study of social interactions involving subjects with Asperger's syndrome that "a lifelong absence of gaze response to social cues including speech could explain a number of the developmental features of autism including lack of joint attention with others, lack of understanding and affective response to others, and poor discrimination of facial expressions" (p. 111). Tantam (1992) has also theorized that a lack of gaze response may also account for the failure of those with autism to develop a "theory of mind." Cowley (1995) gives a simple explanation of "theory of mind," as "an awareness that other people are capable of different mental actions, such as pretending or believing or misunderstanding" (p. 67). Researchers (Baron-Cohen, 1985, 1988; Baron-Cohen, Leslie, & Frith, 1985; Leslie & Frith, 1988, 1990; Perner, Frith, Leslie, & Leekam, 1989), who have devised tests to determine whether a subject understands that other people "can hold false beliefs about the world and that their behaviour can be predicted on the basis of these false beliefs rather than on the basis of what is actually true" (Bowler, 1992, p. 879), have demonstrated that a majority of mentally retarded children with autism lack a first order "theory of mind." Presumably, if one does not understand that another individual has a unique way of understanding the world, one cannot begin to communicate with them.

Theory of Mind Research

The ability to understand that other people are capable of of different mental actions, such as pretending or believing or misunderstanding, appears to exist on an continuum within the autistic population. Baron-Cohen (1989) found that older, less mentally retarded autistic children had a first order theory of mind but not a second order theory of mind ("the ability to predict a protagonist's behaviour on the basis of his or her false belief about another person's true belief about a state of affairs") (Bowler, 1992, p. 879). Bowler (1992) tested the ability of young

adults with Asperger's syndrome to solve problems that required first order theory of mind reasoning and then more problems that required second order theory of mind reasoning. He discovered that the majority of the Asperger's subjects that he tested could solve problems that required second order theory of mind reasoning. Bowler theorizes that the superior cognitive abilities of Asperger's subjects allows them to solve the second order theory of mind problems that he presented in his study (p. 888).

Ozonoff, Rogers, and Pennington (1991) also found that their subjects with Asperger's syndrome could solve first and second order theory of mind problems in formal test situations (p. 1117). However, they discovered that the individuals were much less skilled at quickly applying a theory of mind when informally chatting with the examiner between tests (p. 1118). Bowler (1992) agrees with this informal appraisal of theory of mind skill, warning that "their lack of intuitive knowledge of social behaviour" would still be apparent in real-life social situations that do not allow time for them to compensate cognitive ability for intuitive knowledge (p. 888). Bowler and Worley (1994), in a study of social susceptibility, found that their subjects with Asperger's syndrome were likely to adopt a consistently conforming or nonconforming strategy in response to social pressure. This pattern varied from that of the controls who tended to give a number of conforming responses and also a number of nonconforming responses. The authors cautiously suggest that the consistent pattern in subjects with Asperger's may indicate perseverativeness and also a tendency not to be socially influenced (p. 695). The authors further suggest that the social impairment of people with Asperger's syndrome "may not be a straightforward function of metarepresentation" (p. 696). Not being able to think about thinking, may not fully explain an inability to interact socially. It appears that people with Asperger's

syndrome can think about thinking in formal test situations, but they still have a great deal of difficulty understanding the subtlties of social interaction.

Theoretical Explanations for Autism and Asperger's Syndrome

Relational Deficit Explanation

Hobson (1993) disagrees with the "theory of mind" explanation for the inability of those with autism to relate to other people. He thinks that the inability to relate is the primary deficit and that it causes the lack of a "theory of mind." Hobson states "I think that the autistic children's deficient or aberrant capacity for intersubjective engagement with others is what causes their limitation in understanding minds" (p. 13). Hobson believes that the ability to mentally represent other people's representations (metarepresentation), is part of a social-developmental process that normally occurs, but has gone awry in children who are autistic (pp. 12-13). Since they have not been able to engage with others, they do not understand that other people have subjective experiences and unique psychological orientations to the world (p. 12).

Relevance Theory Explanation

Lack of Central Drive for Coherence

Although those with Asperger's do appear to have a "theory of mind" or some understanding that other people may think differently than they do, they do not seem to be able to use this knowledge quickly in every day, practical situations. Bowler (1992) cautions that although the adults in his study were able to solve problems in which they proved that they were able to "think about thinking about thinking, they were handicapped in their ability to relate to others to such an extent that they required sheltered accommodation and/or employment" (p. 890). Bowler (1992) postulates that this lack of ability to apply knowledge "may result from

what Frith (1989) terms a lack of a "central drive for coherence," i.e., an impaired hypothetical central cognitive process which organizes and coordinates information from memory and a range of sensory and perceptual systems in such a way as to render them of maximum relevance to the psychological task in hand" (p. 890). This would indicate that those with Asperger's are unable to quickly, intuitively attend to the relevant aspects of a situation or a conversation to problem solve or to ascertain the purpose of the interaction.

Frith's (1989) theory that those with Asperger's do not grasp the gist of a conversation because they are not organizing and discarding information according to how relevant it is to understanding (p. 227) seems to explain the difficulty that people with autism and Asperger's have with identifying faces and identifying expressions. Davies, Bishop, Manstead, and Tantam (1994) found that high ability autistic and Asperger's children performed significantly worse than controls at perceiving both facial and nonfacial stimuli, concluding that their results may support Frith's (1989) thesis "that children with autism are unable to combine all the separate threads of information in a stimulus to make a more meaningful whole" (p. 1053). They also believe that their results support suggestions by Miyashita (1988) and Tantam et al. (1989), "that children with autism process faces in terms of their component parts, rather than holistically" (p. 1053).

Cognitive Organization Differs

Happé (1991) suggests that perhaps the brains of autistic individuals are organized in such a manner that they do not need to process information for meaning. She theorizes that one possibility is that the brains of people with autism are wired in such a way that they can acquire all of the stimuli that are in the environment, they have tremendous rote memory skills, and therefore they do not need to be selective (p. 228). Happé further suggests that perhaps the

memory organization of autistic individuals is radically different from most individuals so that they do not follow the same route to storage and retrieval of information that most individuals do, and, therefore, unlike for most individuals, the relevance of the information is not key to its storage and retrieval (p. 228).

Practical Implications of Relevance Theory

Whatever the reason, Asperger's individuals do not intuitively attend to the intended message of a communication. Happé (1991) states that "it is a common observation that autistic people seem to miss what we would regard as salient in a situation, and pay close attention to what seems to us irrelevant" (p. 227). She suggests that highly intelligent people with autism/Asperger's syndrome may learn to recognize certain common social situations by using their intellects and their experiences, but that they do not automatically read the situation for intent and meaning as most people intuitively do. She says that "they may learn to recognize situations where people do not mean what they say-working on simple rules such as:

literally false or puzzling speech + smile = joke

Literally false or puzzling speech + frown = sarcasm" (p. 234).

Having to take time to consciously think through what is happening in a social interaction, rather than immediately, unconsciously, intuitively "reading" the situation would definitely handicap social understanding. Whatever the cause, the social interaction deficit of those with Asperger's syndrome is seriously debilitating.

Research Into Facilitating Personal Interaction Next Step

Current research on Asperger's syndrome has begun to clarify the clinical features of the syndrome, identified social interaction as one of the crucial deficits of the syndrome, and

presented possible hypotheses as to why social interaction is so difficult for someone with Asperger's. It seems that the next logical area for research is in ways that personal interaction can be facilitated for someone with Asperger's. A treatment plan that addressed the crucial deficit of social interaction would be extremely beneficial, especially for adolescents with Asperger's.

Personal Involvement With People With Asperger's Syndrome

Sensing the Barrier as a Teacher

I believe that my first recognizable exposure to someone with Asperger's syndrome occurred in the 1980s, when I was teaching elementary school. One of my students appeared to be socially odd and stiff, with an unusual pattern of learning strengths and weaknesses. As a teacher, I noticed that this Grade 5 student, who I will call John, was having a great deal of difficulty comprehending the main idea of a paragraph, the plot of a story, or even the meaning of questions that asked why, what, or how. At the same time he was able to pick obscure details out of a reading assignment and he could read aloud with perfect pronunciation. I noted that John seemed to enjoy dating each assignment and test that he was given, and that he could tell me the exact date of each particular class assignment that had been given throughout the year. He did not seem to like changes in routine and he was forever asking me what was going to happen next. In order to help John, I gave him extra reading comprehension exercises to do at home and began writing the day's agenda on the classroom board. However, these measures did not seem to change the basic difficulty that John seemed to have with understanding whole concepts and being able to summarize, synthesize, and analyze.

As John's teacher, I also remember the frustration I encountered in trying to impress upon

John's parents that his inability to comprehend the main idea of a paragraph was a serious learning disability. Prior to my expression of concern, they had perceived their son as being very academic since he had performed exceptionally well on all school tasks that required rote learning and memorization of details. For example, John was an excellent speller and he had achieved superior marks in many of the fill-in-the-blank type tests that he had been given at school.

John's classmates also perceived him as being very bright. However, I think that they would also describe him as being a "geek" and a "nerd." He had very little in common with his classmates, who generally were kind to him, but left him alone. John appeared to fit Asperger's description of "the little professor". He wore his shirts tightly buttoned to the collar, when his classmates were lounging in sweats or jeans. While most of the boys in the class were involved in hockey, baseball, and soccer, John could not catch a ball. His movements appeared to be clumsy, awkward, and poorly timed. As a result of his motor clumsiness and his inability to fit in, John spent most of his recesses passively watching the others play.

Besides appearing clumsy and odd, John was difficult to get close to. There did not seem to be a way to have him relax and enjoy the company of his classmates. At the same time that I perceived him as being stiff and awkward, I felt an urge to protect him. He seemed to be so extremely socially naive that I imagined he would be immediately bruised by the world. The invisible barrier that Teacher A described seemed to be present, preventing human contact and yet allowing a clear view of the vulnerable individual underneath.

Although I intuitively noted the differences between John and other students whom I had taught, I was not aware of the term Asperger's syndrome until 1993 when I heard a description of

the disorder in a university class. As the disorder was being described in class, I instantly thought of John. As I have learned more about Asperger's syndrome and I have met individuals who have been given the diagnosis of Asperger's syndrome, I have become convinced that John met the criteria for Asperger's.

University Paper Leads to Professional Involvement with Asperger's

I was intrigued by the description of Asperger's syndrome which was presented in that 1993 university class and as a result I chose Asperger's as the topic of the paper that was required for the class. My choice of paper topic was serendipitous, being the first step in a path that has lead to extensive professional involvement with individuals with Asperger's syndrome and eventually to the writing of this thesis. It seems that my initial interest has evolved into a major component of my life.

The first university paper that I wrote about Asperger's syndrome was instrumental in helping me to secure employment in the fall of 1994. I had discussed the paper with a teacher friend and when she learned that a teacher/counsellor was required in her school division to work with a boy who had been diagnosed as having Asperger's syndrome, she advised me of the job opportunity. I submitted my paper on Asperger's syndrome with my résumé, I was granted an interview, and I was employed with the mandate of establishing a relationship with a junior high boy who refused to go to school and who had recently been diagnosed as having Asperger's syndrome.

Thus, I met Martin [sic], the child of Parent A. I was introduced to Martin by the school psychologist who had been involved with him at school. The three of us met for a mid-afternoon snack. During our meeting, Martin dominated the conversation, interjecting inappropriate

comments, bizarre topics, or swear words when the school psychologist and I began to talk to each other. This pattern of demanding to be the focus of attention and being unable to deal with three-way conversations continued throughout my involvement with Martin. During this initial conversation, Martin persisted in talking about all-terrain vehicles. I learned that his favourite place in the world was his family cottage at the lake, where he could ride all-terrain vehicles and enjoy a sense of freedom. Martin's interest in all-terrain vehicles gave me a entry and we agreed to meet the next day, planning to visit a store that sold these vehicles.

My first task in establishing a relationship with Martin was to get him out of bed. During the fall of 1994 he had begun a pattern of staying up until 4:00 A.M., watching television, and then sleeping for twelve hours, effectively sleeping through the hours that school was in session. He had also retreated to the basement to sleep, where he had darkened the windows, and placed a television at the foot of his bed. His mother described his sleeping behaviour as *"retreating to his cave to hide from the world."* It was my task to get him out of his cave.

Initially, I got Martin out of bed each afternoon by giving him two warning phone calls and then arriving at his house to engage him in an activity that he had expressed an interest in and that we had both agreed to. Sometimes this involved an outing to a place of interest, such as the all-terrain vehicle store, and other times this involved an activity in his home, such as watching one of his favourite movies or reading a script aloud. Gradually, through this process, I learned more about Martin.

Martin had fantastic verbal skills. He had memorized lines from many television commercials, movies, and songs, as well as entire skits and jokes. He had an enormous vocabulary and his pronunciation was impeccable. He seemed to enjoy using his verbal skills to

entertain and impress people. He would often do voice impressions of movie characters. Martin had been using his verbal abilities in a children's drama group for many years. As we drove from place to place, Martin used his extensive repertoire of voices and lines to entertain me.

Martin was not afraid to broach any topic. He did not seem to keep thoughts or feelings to himself. In our third meeting he told me that he often felt depressed and that he had thought about suicide. He even described his suicide plan. He often had to be told that his chosen topic of conversation was inappropriate, rude, crude, or embarrassing. Martin seemed to be extremely open and incapable of subterfuge.

Martin openly told me about some of the rage that he had experienced in the past. He liked to present himself as a good fighter, saying that he had a boxer's injury on his hand from all of the fights he had been in. In reality he had expressed his anger and frustration at school by punching a window and at home by pushing and kicking the walls. At one point his parents had had him arrested for trashing their house. Martin was actually very frightened by the arrest and from time to time he would talk about the fear and humiliation he felt in the juvenile detention centre. Although Martin boasted about his prowess as a fighter, his mother and the school psychologist reported that Martin generally ran away from threatening peers. In unfamiliar environments or with peers he may have regarded as threatening, I have seen Martin physically draw himself together in a self-protective manner. I can picture him shuffling down the hall, with his head down and his arms hanging ineffectively at his sides. Rather than being intimidating, Martin was a frightened, lonely boy, who was unable to connect with his peers.

Martin spoke to me about the loneliness he experienced each day. When I first met him, he was a twelve-year-old who had almost no contact with his peers since he did not attend

school. His past experience with children of his own age involved hurt, frustration, and anger, since he was often teased and he did not have the skills to reciprocally interact with his peers. I noticed that when he was given the opportunity to interact with peers, he did not. Instead, he kept to himself or chose to speak to any adult who was present. Martin would generally strike up a conversation with any adult that he encountered. These conversations could go on for quite some time because Martin was well spoken and he had a wealth of knowledge about a variety of topics to sustain the conversation. It seemed that Martin's verbal skills allowed him to have contact with adults, but that this strength was not a sufficient basis for peer friendships.

Although Martin expressed a keen interest in all-terrain vehicles during our first meeting, this was not his only area of interest and he did not use all-terrain vehicles as a topic of interest and conversation with everyone he met. Martin tended to be intensely interested in one topic or activity for a period of time and then move on to another preoccupation. While he was in the midst of one interest, it was very difficult to move him to another activity. During the time that I was working with him, he showed intense, exclusive interest in: all-terrain vehicles, electric bass guitars, snowboards, tattoos, and smoking. Martin became very knowledgeable about each of his topics of interest, and he would engage sales people in long question and answer sessions around his preoccupation. Prior to entering a store with Martin, it was important to discuss time lines and my agenda, so that Martin would not spend hours talking to the sales staff. Even so, a lot of effort was required to persuade Martin to compromise his agenda.

One absolute block for Martin was school work. In particular Martin expressed a dislike for mathematics and any activity involving the use of a pen or a pencil. Martin enjoyed using his home computer to explore the Internet, but he quickly became frustrated with keyboarding. It

appeared that Martin had extremely poor fine motor skills and minimal mathematics skills. He could not figure out how much money he should give a salesclerk or what change he should receive. Moving Martin towards engaging in school-like activities proved to be the most difficult component of my job.

In time, a curriculum consultant and I tried to use Martin's areas of interest to move him towards engaging in a school-like activity and to have him enter a school building. Some of the activities we tried were: using an office in a school as a writing room for Martin and I, having Martin act as a computer tutor on a one-to-one basis in a school library, having Martin and I work as teacher aids in a French immersion classroom, and returning Martin to his elementary school, where he played with children in the counsellors office and used the library computer filing system. In all of these activities Martin needed my supervision and intervention. The most successful activity, as far as producing a school-like paper assignment, was the writing project. Martin wrote a short comedy skit called "Obfuscate an Ox". It was heavily based on the Monty Python skit, "Confuse a Rabbit" and I typed most of it, with Martin dictating. However, there was a product and, for a time, Martin was excited about producing it as a play.

Unfortunately, Martin lost interest in each project and refused to participate, leaving me to tutor the child on the computer or follow the teacher's instructions. In some cases, it seemed to be Martin's egocentricity that caused problems. As a twelve-year-old he wanted to play the computer himself rather than accommodate to a seven-year-old. In the guidance office Martin wanted to choose the game to play with his six-year-old companion. In other cases, Martin encountered difficulties because he did not monitor his language or his behaviour. In one school he was reprimanded for swearing in the photocopy room. He then became very angry with the

people in the school and refused to return. In each case, Martin seemed unable or unwilling to bend to the demands of the school environment.

Luckily, Martin did find a school that he wanted to attend and a program that met his needs. In the spring of 1995 we began exploring options for Martin for the 1995/96 school year. Martin liked the idea of attending a collegiate, where he could possibly have more flexible programming and begin to be integrated back into school by attending only a few classes in subject areas that interested him, such as Automotive Mechanics or Drama. When we visited a collegiate that he could possibly attend in the fall of 1995, Martin announced that he really liked the atmosphere and that this school was the one that he wanted to attend. Somehow Martin felt that he would fit in this collegiate environment, with older students who were more like adults than children.

Martin's acceptance into the Autism Program in this collegiate did not mean the end of my involvement with him or with Asperger's syndrome. Instead, it lead to a more intensive level of involvement. In the fall of 1995 I began to work as a teacher aid in the Autism Program at this collegiate, and, thus, my connection with Martin continued and I began to meet and work with other students who had been diagnosed as having Asperger's. As a teacher aid, I spent many hours tutoring some of these students, such as David and Adolescent A, on an individual basis. I began to compare Martin, David, Adolescent A, and other individuals with Asperger's who were members of the Autism Program. Gradually, my sense of what Asperger's meant to those who had been given the label and to those who were professionally and personally involved with them developed. Finally, I arrived at the point where I wanted to make Asperger's syndrome the subject of my thesis. I had personally experienced the tragedy of these adolescents who

desperately wanted to connect with their peers, but could not. Developing personal interaction plans for adolescents with Asperger's syndrome became the logical solution to their dilemma and the subject of my thesis.

Rationale

Why Adolescents With Asperger's

Adolescent Developmental Stage Crucial for Intervention

Adolescents with Asperger's syndrome became the focus of my study for practical and logical reasons. Practically, they were the population with whom I was working, but more importantly, adolescence is a crucial time for intervention for those with Asperger's syndrome. Adolescence is a key developmental time period that impacts on the future psychological health of every individual. It seems to be especially crucial for those with Asperger's syndrome. Adolescence is a developmental stage where people are particularly drawn to their peers. Unfortunately, adolescents with Asperger's are handicapped by the reciprocal social interaction deficit of Asperger's and are unable to make the social connection with peers that is so necessary at this stage of development. Tantam (1991) states: "Asperger's syndrome may cause the greatest disablement in adolescence and young adulthood, when successful social relationships are the key to almost every achievement" (p. 148). The natural desire to connect with peers at adolescence may motivate adolescents with Asperger's to try to approach their peers. Thus, adolescence is a crucial time to have personal interaction plans in place for those with Asperger's, so that they may begin to make successful connections with their peers. Without any possibility of positive peer interaction, adolescence may be a particularly difficult time for those with Asperger's syndrome.

Deteriorating Psychological Health at Adolescence

Researchers have noted the deterioration in psychological health that adolescents with Asperger's may encounter. Berthier, Santamaria, Encabo, and Tolosa (1992) give a summary of previous findings in this regard. They report that although researchers, (Bishop, 1989; Szatmari, et al, 1990), have noted that the diagnosis of Asperger's syndrome has a considerably better prognosis that that of Autistic Disorder, effected individuals may be predisposed to develop other psychiatric disturbances (p.735). They cite Gillberg (1990) as stating that a substantial number of individuals with Asperger's deteriorate psychologically at adolescence (p. 735). Berthier et al. give the following list of psychological problems that may be encountered by adolescents with Asperger's syndrome and the researchers who have reported each type of problem: affective illness and anxiety (Tantam, 1988), antisocial behaviour (Baron-Cohen, 1988; Everall & LeCouteur, 1990; Marson, et al, 1985; Wolff & Cull, 1986), and psychotic symptoms (Clarke et al., 1989) (p. 735). Berthier et al., in their own 1992 study, reported the co-existence of Asperger's syndrome and Kleine-Levin syndrome in two male adolescents. Both of the subjects in the Berthier et al. study had been diagnosed as having Asperger's syndrome as children and began displaying symptoms of Kleine-Levin syndrome, such as "hypersomnia, compulsive eating, and disturbances in behaviour, cognition, and mood" (p. 735), in adolescence. It appears that adolescents with Asperger's are particularly vulnerable to a deterioration in psychological health.

Martin's behaviour, when I first met him, of retreating to his dark, basement hide-away to sleep away the daylight, school hours, could certainly be interpreted as a symptom of depression. Many of the students in the Autism Program had been admitted to psychiatric facilities at some

point in their adolescence. During the spring of 1996, a girl in the program, Nancy [sic], who was perseverative about police officers and violence, was admitted to the psychiatric ward of a local hospital. Each member of the Autism Program, except one, was on at least one type of medication, ranging from anti-anxiety medication to anti-psychotic medication. A few of the students were taking up to six different medications, giving them a chemical cocktail to control their anxiety, depression, bizarre thoughts, and obsessions. It seems that the triad of impairments of autism or Asperger's syndrome, including "reciprocal social interaction, verbal and nonverbal communication, and restricted range of imaginative activities" (Szatmari, 1991, p. 82), may lead to secondary psychological health problems, such as anxiety, depression, and obsessive compulsive disorder.

Diagnosis an Issue at Adolescence

Asperger's May Mimic Mental Illness

The triad of impairments of someone with Asperger's syndrome may also be interpreted as being the symptoms of someone with a psychiatric illness. In the 1960s Sula Wolff began to diagnose schizoid personality when she encountered children who met the following characteristics: "solitariness, lack of empathy, abnormal sensitivity, rigidity of mental set, especially pervasive interest in patterns, and unusual communications" (Wolff & McGuire, 1995, p. 793). Later, Wolff and Chick (1980) added the feature "unusual fantasy" to characterize the boys with the disorder (Wolff & McGuire, p. 793). Although by 1980 she recognized a great many similarities between her description of schizoid personality disorder and the autistic disorder that Asperger described in his 1944 paper, Wolff continues to give the label schizoid personality disorder to children with these features (Wolff & McGuire, 1995).

Perhaps many people who could be diagnosed as having Asperger's syndrome have been given other diagnoses such as schizoid personality disorder. Certainly, Teacher B has noticed a change in diagnosis over the years that he has worked with this population. When I asked him when he had first encountered someone with Asperger's, he replied:

> *Well again, my experience is that all of the students when I first started were diagnosed as Childhood Schizophrenics. And then it changed over to Pervasive Developmental Disorder, autism, Asperger's syndrome. So I think that I recognized many years ago. And then, once I clarified the diagnosis in my head, I knew that some of the kids that I'd seen years ago were Asperger's, but probably misdiagnosed by the people who were diagnosing them. So probably since the beginning of working with them, I've been noticing them.*

Ryan (1992) alerts clinicians to the possibility that treatment resistant mental illness may be an indication that the client was misdiagnosed as mentally ill, and that Asperger's syndrome should be considered in re-diagnosis since this condition may superficially mimic mental illness. Ryan states that the "eccentricities, emotional lability, anxiety, poor social functioning, repetitive behaviour, and fixed habits [of someone with Asperger's syndrome] may mimic symptoms of other illnesses, including schizophrenia spectrum illness, bipolar disorder, anxiety disorders, and obsessive-compulsive disorder" (p. 807).

Sometimes clinician do recognize Asperger's syndrome in the midst of features which could be interpreted as mental illness. Atlas and Gerbino-Rosen (1995) report the case of a sixteen-year-old girl who was admitted to their acute psychiatric unit showing "manic mood, flight of ideas, gaze aversion, and interpersonal intrusiveness" (p. 207). They used her early

history of "touch avoidance, gaze aversion, perseverativeness, and other behavioural features suggestive of Autistic Disorder" (p. 207) coupled with "age-appropriate language skills and cognition, motor clumsiness, and yearning for relating to others" (p. 208) to give her the diagnostic label Asperger's syndrome. Conceivably, this girl and other adolescents like her could be given a number of mental illness labels.

Since Asperger's syndrome is a subtle disability, it may not be accurately diagnosed. Often people with Asperger's syndrome do not receive any sort of diagnosis until adolescence or adulthood, when, as Tantam (1991) states: "Abnormalities that are mild enough to be disregarded in childhood may become much more conspicuous, leading to a specialist opinion being sought for the first time" (p. 148). They may have had a number of previous diagnoses prior to being labelled as being Asperger's and they may continue to be given different labels, including ones that categorize them as mentally ill. Tragically, it may be the secondary features of autism or Asperger's that mimic the features of mental illness that first bring those with Asperger's to the attention of mental health practitioners. By the time those with Asperger's seek help for their anxiety, depression, or obsessions, these features may dominate the clinical picture and obscure a diagnosis of Asperger's.

Adolescence May be Time of Diagnosis

Adolescence is the time that people with Asperger's begin to come to the attention of the mental health community for a number of reasons. Pope (1993) links the failure to obtain friends at adolescence by people with Higher Functioning Autism with affective disorders:

> Higher functioning patients who wish for friends may feel isolated and even hopeless because of their deficits. Depressive episodes in adolescence are not uncommon, and

these children are at a higher risk for the development of mood disorders. (p. 103)

It seems that by adolescence, with the opportunity for maturation and experience, these more intelligent people with autism are gaining some insight into their disability and the impact of being friendless. Capps, Sigman, and Yirmiya (1995) found that "social competence is lower among autistic children than typically developed children, and lowest among the most highly intelligent autistic children" and interpreted these results to mean "autistic persons who are more intelligent and better able to read the emotions of others may acquire greater awareness of qualities that differentiate them from normal people" (p. 144). Unfortunately, awareness of their difficulties without any hope of improvement, may lead to hopelessness and helplessness or rage.

Risk of Violent, Anti-Social Behaviour by Adolescents with Asperger's

Caused by Rage and Frustration

Each of the participants in my study mentioned frustration and anger as being very evident in lives of adolescents with Asperger's. Sometimes this rage leads to destructive acts, such as the *"trashing of the classroom"* that Adolescent A describes. Both Parent A and Parent B have had to deal with destruction of walls, pictures, and furniture in their homes by their adolescent children with Asperger's. Parent A and her husband chose to have their son arrested when he violently attacked the walls in their home, while Parent B states that her daughter can not live at home because she and her husband can not keep her safe and stop her destructive rages. I have personally heard Martin threaten to kill his parents if they did not give him the presents he wanted for Christmas and Parent B recalls that when her daughter was admitted to the hospital she was threatening to kill both herself and her mother with a knife. Even Adult A, who describes himself as *"stiff assed"* and who appears to be very law-abiding and rigidly

conforming, talks about the frustration he felt as an adolescent.

A: *But the biggest problem was . . . I wasn't moving. There wasn't enough challenging subjects that I was taking, and enough academics and that sort of thing. It took me a long time to realize, when my Mum took me out of Jason Brown Collegiate* [sic] *that that was . . . ., I guess, in my best interest. You know at the time I was rebelling.*

I: *MmmmHmmm.*

A: *I mean, at that age, I rebelled against almost every authority.*

I: *Really! You wouldn't know that from talking to you now.*

A: *I rebelled. Oh, oh I was a rebel!*

Nancy, who was admitted to a local hospital's psychiatric ward in the spring of 1996, reportedly attacked both her mother and a security guard prior to her hospitalization. Dewey (1991) explains hostile reactions in individuals with Asperger's by stating: "A child who is often rejected and tormented may well develop hostile defences" (p. 194). It appears that adolescents with Asperger's may become so frustrated that they act-out by destroying property or by hurting people.

Caused by Rigid, Egocentric Thinking Pattern

Sometimes the rigid, egocentric thinking of individuals with Asperger's may lead them to participate in anti-social activities. Everall and LeCouteur (1990) present a case study of a sixteen-year-old with Asperger's syndrome who showed no remorse after he was caught fire setting. They report that the sixteen-year-old was not obsessed with fires, but that he saw no reason why he should not continue with what he thought was an interesting activity. His self-centred explanation and his inability to consider the effect of his action on other people were the

authors' main areas of concern. Other people with Asperger's syndrome may find themselves participating in illegal, anti-social activities for similar reasons. Nancy's attack on the security guard may have been caused by her interest in policemen and violence and her insistence in carrying out her own agenda, without considering the consequences of her actions. When people with Asperger's rigidly follow their own agendas and interests without considering what effect their actions may have on other people, they may occasionally be performing illegal activities. Frith (1991) explains why individuals with Asperger's may commit criminal offences: "Sometimes their offences are part of their single-minded pursuit of a special interest, sometimes the result of a defensive panic-induced action and sometimes the consequence of a complete lack of common sense" (p. 25) Adolescence may be a time when those with Asperger's syndrome find themselves in trouble with the law.

Adolescence Time of Opportunity for Intervention

However, adolescence does not have to be the beginning of a negative spiral for individuals with Asperger's. The awareness that may begin to emerge at adolescence for individuals with HFA or Asperger's may have positive consequences. Kanner (1973) realized that an increasing awareness of their differences from most other people could have a positive outcome for those with autism. He asserted that "[his] most successful autistic patients, unlike most other autistic children, became uneasily aware of their peculiarities, and began to make a conscious effort to do something about them" (in Capps, Sigman, & Yirmiya, 1995, p. 139). There may be hope for the sixteen-year-old fire setter because, although he showed no remorse for fire setting, his mother described an improvement in his social behaviour, "reporting that he had gained some insight into his social difficulties resulting in him feeling embarrassed at times"

(Everall & LeCouteur, 1990, p. 285). Adolescents with autism or Asperger's syndrome, who are able to perceive their autistic qualities, may be able to seize an opportunity to adopt action plans that would enhance their lives. Since the motivation to interact with one's peers is strong and the consequence of not being able to do so may be severe, adolescence is the time to have achievable personal interaction plans in place for those with Asperger's syndrome. Research that describes and presents a critique of such plans would be a valuable contribution to the literature on Asperger's. It would provide clinicians, teachers, parents, and individuals with Asperger's with a guide to facilitation the personal interaction that adolescents with Asperger's so desperately need.

Why a Qualitative Study

I have taken a qualitative approach to this study for practical, historical, and philosophical reasons. From a practical point of view, I have had the opportunity to be part of a qualitative, case study-type, research project, having been immersed in the daily lives of adolescents with Asperger's syndrome for eighteen months. Historically, an understanding of Asperger's syndrome has developed through the presentation of case studies, beginning with Asperger's own account in 1944. Philosophically, I believe in the power of descriptive language to convey meaning. I think that people can begin to understand Asperger's syndrome by being able to form a mental picture of a variety of individuals with Asperger's. Frith (1991) explains the value of descriptive case studies when she states:

> At this stage it is largely through detailed case studies that we can begin to understand the syndrome. Just as one comes to recognize a Mondrian painting by looking at other Mondrians, one can learn to recognize a patient with Asperger syndrome by looking at cases described by Asperger and other clinicians. (p. 1)

I would like to present the interview data from the eight interviews that I conducted in such a manner that the readers of this thesis gain an understanding of Asperger's syndrome and how personal interaction plans may be used to build connections with peers for adolescents with Asperger's. I hope by presenting a rich description of nine people's experiences with Asperger's (the eight interviewees' plus mine) that the readers of this thesis will incorporate these experiences into their own data bases and so increase their understanding of Asperger's. Stake (1994) states that "case study researchers assist readers in the construction of knowledge" (p. 240). He justifies this statement by explaining how readers may construct knowledge: "Certain descriptions and assertions are assimilated by readers into memory. When the researcher's narrative provides opportunity for vicarious experience, readers extend their memories of happenings" (p. 240). Stake and Trumbull (1982) termed this process, "where a reader comes to know some things told as if he or she had experienced them, naturalistic generalization" (Stake, p. 240). Therefore, according to Stake and other constructivist researchers, a research report that provides a rich description of people and places may enable the reader to make naturalistic generalizations and to reach an understanding of the phenomenon that the researcher is describing. My objective in presenting a qualitative thesis is to have the readers of this report reach such an understanding of Asperger's syndrome.

METHOD

Participants

Who They Are

I interviewed eight people in the data gathering stage of this thesis. The people who I interviewed were all personally or professionally involved with adolescents with Asperger's syndrome. The eight participants included: an eighteen-year-old with Asperger's syndrome (Adolescent A), a twenty-three-year-old with Asperger's syndrome (Adult A), a parent who's adolescent son had been diagnosed as having Asperger's syndrome (Parent A), a parent who's adolescent daughter had been diagnosed as having Asperger's syndrome (Parent B), a teacher assistant who had tutored adolescents with Asperger's syndrome, on a one-to-one basis for 4 years (Teacher Assistant A), a teacher with many years of teaching in mainstream classes, who had been co-directing the Autism Program for 2 years (Teacher A), a teacher with many years of experience teaching children with PDD characteristics in alternative classrooms, who was the other director of the Autism Program (Teacher B), and a speech and language pathologist, who had been providing speech and language therapy to children with autism and Asperger's syndrome since 1982 (Speech and Language Pathologist A).

I met each of these eight participants through my employment from 1994 to 1996. Parent A is the mother of Martin, the junior high boy who I was initially hired to work with. Adolescent A is a member of the Autism Program, Teacher A and Teacher B are the co-directors of the Autism Program, and Teacher Assistant A and I were both teacher assistants in the Autism Program. Adult A has been Teacher B's student for many years and he still drops into the Autism Program several times a week to consult with Teacher B, study, and help with a flyer

delivery route. Parent B is the mother of Jane, an eighteen-year-old member of the Autism Program. Speech and Language Pathologist A is the speech and language pathologist who serves the Autism Program. Each of the participants has a connection with the Autism Program, where I worked as a teacher assistant during the 1995/96 school year.

In a way, the Autism Program acts as a case study and the basis of this study. Because each of the participants was connected to the Autism Program in some way, they often describe the same people and the same situations in their interviews. Although David, Jane, Martin, Nancy, and Frank were not interviewed for this study, they, along with Adolescent A and Adult A, were all members of the Autism Program and descriptions of their experiences with Asperger's syndrome form part of the basis of this paper. Each of these students or ex-students form part of the participants understanding of Asperger's syndrome. Teachers A and B, Speech and Language Pathologist A, and Teacher Assistant A have all had professional contact with each of these students. Parents A and B, obviously have a great deal of experience with their own children, Martin and Jane, but they have also learned something of the other students in the program through parental involvement with the program. Adolescent A and Adult A have spent years with the other students in the Autism Program, and they have each worked individually with Teachers A and B, Teacher Assistant A, Speech and Language Pathologist A, and I. There is an interconnection, through the Autism Program of each participant, including myself.

How They Were Recruited

After I had decided that I wanted to interview people with personal or professional experience with Asperger's syndrome for my thesis, and I had received consent for my thesis proposal from my thesis committee and also from the Research and Ethics Committee, Faculty of

Education, University of Manitoba, I approached six people and asked them if they would be interested in being interviewed about Asperger's syndrome. These six people were: Adolescent A, Adult A, Parent A, Teacher A, Teacher Assistant A, and Speech and Language Pathologist A. At this time, I also explained that the interview would be tape-recorded and that the data from the interview would be used as the basis of the research for my master's thesis. I asked everyone, including Adolescent A and Adult A, to think carefully about my request and I pointed out to them that they were free to choose not to participate. When each of the participants agreed to be interviewed, I set up an interview time and place with them. I met with Teacher A, Adult A, and Adolescent A on separate occasions, individually, privately in classrooms after school. Parent A and Teacher Assistant A chose to meet when they were alone in their own homes. Speech and Language Pathologist A and I met alone in a meeting room at her central office. I met each of the participants at his or her convenience.

At the beginning of each meeting with a participant I thanked him or her for taking the time to be interviewed and I asked that an information letter and consent form (Appendix D) be read and signed before the interview began. The information letter outlined the nature of my research and the topics of the questions that I would be asking in the interview. I explained that the interview would be tape-recorded and that the data from the interview would be used in my thesis as anecdotes and as the basis for analysis. I acknowledged that if the interviewee did not want the interview to be tape-recorded, I would not proceed with the interview and that he or she would not be included as a participant in the study. I gave an approximate time for the interview of forty-five to sixty minutes and explained that there would be two mini-interviews of approximately ten minutes to clarify data and to discuss interpretations. I explained that I would

keep personal information confidential during the study by not using the participant's name or identifying information in my data notes or in the thesis, and that I would erase the audio-tapes once the research was completed. I also clearly stated that the interviewee had the right to refuse to answer any questions, to end the interview at any time, and to opt out of the study at any time. Each interviewee was given the option of reading a copy of his or her interview transcript and assured that portions of the interview would be deleted at his or her request. I stated that I planned to send each participant a summary of the results of this research. All six potential interviewees read the information letter and formally agreed to be interviewed by signing the consent form.

After I had interviewed the first six participants, I decided that I would also interview Teacher B and Parent B. The decisions to include two more participants were based on information that I gathered during the study. After I had interviewed a number of people who had referred to Teacher B in their interviews and I learned of his long-term involvement with individuals with Asperger's syndrome, I decided that an interview with him would add depth to my data. In addition, I thought it was important to interview both of the co-directors of the Autism Program. I decided to interview Parent B after I learned that there was controversy around the diagnosis of Asperger's syndrome for Martin, the child of Parent A. I was referred to Parent B by Teacher B and by the Special Education Coordinator in the collegiate, both of whom knew her and who had had professional experience with her daughter, Jane. I followed the same procedure as I had with the other six participants in gaining informed consent from both Parent B and Teacher B to participate in the study. I interviewed Teacher B on two occasions in a classroom, early in the morning before school started, and I interviewed Parent B in her own

home. With the completion of these two interviews, I had the audio-taped data that I would use as the basis of my thesis.

Interviews

Interview Format

In each of the eight interviews I asked questions around three basic topics. I asked each participant how he or she understands and makes meaning out of Asperger's syndrome, what he or she has noticed about the personal interactions of adolescents with Asperger's syndrome, and what he or she believes would facilitate personal interactions with peers by adolescents with Asperger's. I also asked each participant about his or her history of involvement with individuals with Asperger's syndrome. I asked Parents A and B when they had first been given the diagnostic label, Asperger's syndrome, for their children, I asked Adolescent A and Adult A when they had first heard the term Asperger's applied to themselves, and I asked the other four participants when they had first started working with individuals with Asperger's syndrome. I asked each participant, except Adolescent A and Adult A, to reflect about how Asperger's syndrome effects him or her personally. I wanted to know if the participants thought they had changed as they had gained experience working with adolescents with Asperger's. Obviously, the entire interview of Adolescent A and Adult A was a reflection of personal experience with the syndrome. All of the participants were asked the same general questions, but the wording of the questions depended on the orientation of the interviewee.

I went to each interview with a list of written questions to ask that particular participant. I had a total of six slightly different interview protocols (Appendix E), one for each of the following people: adolescent, adult, parent, teacher, teacher assistant, and speech and language

pathologist. Each set of questions was similar to those for Adult A, with the orientation changing according to who I was interviewing. My written questions for Adult A asked: what it means to him to have Asperger's syndrome, what it meant to him when he first became aware that he was in some way different from other people, how he experienced adolescence with Asperger's, how he has changed since adolescence, what he learned about interacting with others as an adolescent in an autism program, what advice he would give to teachers who are planning personal interactions for adolescents with Asperger's, and what he has learned about interacting with others since he left the autism program. I asked each of the participants all of the questions on his or her interview protocol. Sometimes I added extra questions as the interview proceeded to clarify an answer or to pursue a particular line of thought. I also encouraged each participant to tell anecdotes to illustrate his or her answers. I responded to the participants' answers and anecdotes with my own body language, encouraging comments, and the occasional remark. In this way, each interview included the same key questions, but varied from each other interview according to the perspective of the interviewee, the nature of my supplemental questions and verbal and non-verbal responses, and the direction that interviewee's responses lead us. Each interview was structured by the written questions, but open-ended in terms of the participant's responses and the nature of the developing dialogue between the participant and I.

There was a great deal of variety between the interviews. They varied in length from forty to eighty minutes. In some cases, I spoke very little, primarily asking the written interview questions and then allowing the participant to reply in length. In other cases, I had to rephrase my questions or make encouraging comments to elicit an answer from the participant. Sometimes, I had to refocus the interview and ask the next written question to bring the dialogue

back on topic. From time to time, I asked questions to broaden or deepen the dialogue. My emotional response to the participant varied during each interview, and from interview to interview. At various times I found myself feeling profoundly moved, sad, bored, surprised, and fascinated. Exactly the same question elicited a variety of responses from the participants. There is a wealth of material to be analyzed in the eight audio-tapes from the interviews.

Analysis of Interviews

Observer During the Interview

My analysis of the interviews began as I was interviewing each participant. During each interview I was an observer, as well as an interviewer. I observed how each participant responded to my questions with his or her body language, facial expression, tone of voice, and response time. I also observed my own response to the participant and to the interview, in terms of my outer responses of body language and tone of voice and inner responses of emotion and thought. I took note of which questions elicited a quick, easy response, and which questions produced a pause and a shifting of eyes by the participant. I noted my feelings of surprise or fascination and the direction that my thoughts moved after certain statements by the interviewee. As each interview proceeded, data analysis occurred. Following each interview I wrote a journal entry recording my impressions of the interview.

Transcribing Engrained Content and Texture of Interview

After each interview I began to transcribe the audio-tape of the interview. This process involved listening to each sentence that the participant and I spoke several times so that I could record it exactly. The listening and re-listening to each segment of the tape, sentence by sentence, engrained the interview into my mind. Once again, I heard each change of tone of

voice and each pause in the conversation. By the time I had completely transcribed an interview, I could hear the interview in my mind as I read the words on the printed page. As I transcribed each interview, in this slow, painstaking manner, I could not help but absorb and internalize what I was hearing and writing. Indeed, to change the spoken interview to a written page, I had to decide how to interpret speech patterns in a written form. I began to put slash marks where people changed topics mid-sentence, commas where there was a slight pause, and a serious of dots to represent longer pauses. I added exclamation marks where participants made particularly vigorous comments and I highlighted words in bold type that the participants said with great emphasis. I included every word that I could hear on the tape, including *MmmmHmmm,* habitual words, such as *You know?*, and swear words. Some of my written interpretations did not make grammatical sense, but they conveyed the rhythm of the conversation. By deciding how to interpret the spoken interview in written form, I was continuing to analyze each interview. In addition, I was gaining a memory data bank of each inflection in each sentence in each interview. From time to time, I added comments, reflecting my thoughts and feelings as I transcribed the audio-tapes, in the thesis log that I was keeping.

Memory Bank of Previous Interviews Allowed Continuous Analysis

After I had completed my first interview, I had the memory of that interview to use in subsequent interviews. I tried not to tell one participant what another participant had said, but as I completed more and more interviews, I found that I was comparing and contrasting what the previous participants had said to what the current participant was saying. This happened in my observer role in the interview. While I was listening to a participant's answer, I could think, *"That's interesting, the last person I interviewed mentioned that, too."* Occasionally, I did use

what I knew about a previous interview, to add a supplemental question or pursue a line of thought. For example, in Adult A's interview, when Adult A said:

> *I was too naive back then. And I guess, that is always a trap you can get caught in. I mean sometimes people appear to be this, and then they ain't all that. You know, they ain't/*

I thought of Adolescent A's comment about getting *"burned"* in the past when he tried to initiate friendships. I clarified what I thought Adult A meant by his comments and then I decided to mention Adolescent A's similar experience to Adult A. Our conversation went like this:

> *I: MmmmHmmm. So, have some bad experiences taught you that you have to be careful?*
>
> *A: Yeah. Yes! Oh, yes!*
>
> *I: So, and as you have got older, you have learned from some of those experiences, and figured out that, you know, you have to be a little bit careful around people.*
>
> *A: Oh, yes!*
>
> *I: Sometimes you get burned.*
>
> *A: Oh, yes!*
>
> *I: Ummm, when I was talking to Adolescent A* [sic], *he was saying that his attitude is that he waits for someone to come to him because he has got burned too many times. So he doesn't go out and try and make friends.*
>
> *A: You know that is the unfortunate thing for me is that right now I think I'm not aggressive enough. And that is the trap that you can get trapped in and Adolescent A* [sic], *can get trapped in, if he just waits. You've got to let your guard down a little bit.*

This is the most concrete reference that I made to another participant's interview, but I did make other less obvious oral comparisons during other interviews. However, by far the majority of analysis was occurring in my head, as I used an ever growing data bank of material from previous interviews to reflect on what was happening in the present interview.

The interviews occurred in the following order: Teacher A, Parent A, Speech and Language Pathologist A, Adolescent A, Adult A, Teacher Assistant A, Teacher B, and Parent B. The first interview with Teacher A and the last interview with Parent B were twelve weeks apart. During this three month period I conducted all eight interviews and transcribed six of the interview audio-tapes. The last two audio-tapes were transcribed during a three week period following Parent B's interview. Each audio-tape took a minimum of eight hours to transcribe, so that during this fifteen week period, I was spending a great deal of time immersed in the subject matter of my thesis. I have a total of 197 pages of transcript from the eight interviews. The comments of each person are single spaced, with double spacing indicating a change of speaker. There is a great deal of data from the interviews.

Post-Interviews and Post-Transcription Analysis

Mini-Interviews

After I had transcribed each interview I gave the interviewee a copy of the transcription and asked him or her to read it and give me feedback. The mini-interviews, where each participant commented on his or her reaction to reading the transcript of our interview, added to my research data. Some people made corrections to spelling and details in the transcript. Other people commented on how the literal transcript of the interview pointed out patterns in their own speech. A few people asked that sections of their transcript be deleted. There were some

comments that summarized the impression that the transcript gave them about what they were saying about Asperger's syndrome. The mini-interviews were a useful check on my interpretation of the interviews.

Formal Analysis of Interview Data

After I had completed transcribing all eight interviews, I began to formally analyze the data by organizing it into categories and themes. My first categorization was to list all of the statements in the transcripts that seemed to match or pertain to the DSM-IV diagnostic criteria for Asperger's syndrome. I listed the statements from the transcripts under the following headings: (a) Qualitative impairment in social interaction, (b) Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, (c) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning, (d) There is no clinically significant general delay in language, (e) There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood, and (f) Criteria is not met for another specific Pervasive Developmental Disorder or Schizophrenia. While I was categorizing diagnostic statements from the interviews according to DSM-IV criteria, I noticed that some of the interviewees' statements seemed to indicate alternative criteria for diagnosis, so I added another heading to my list called, Other Suggested Diagnostic Criteria. My second way of organizing the data was to look for themes in the interviewees' statements about treatment plans for adolescents with Asperger's. My initial headings in this section included: (a) Developing a healthy self-perception, (b) Developing an understanding of social interaction by studying people and their behaviours and feelings, and by

studying social situations, (c) Developing avenues for social interaction, (d) Finding an area of special interest, a niche, and (e) Providing a means to structure the world. After I had developed these categories, I read all of the transcripts again and I listed other ideas that seemed to be prevalent in the participants' thinking about Asperger's. The new list included the following headings: (a) Ideal apprentice people, (b) Culture of autism, (c) Advocates, and (d) Value of social interaction with each other. By reading and re-reading the transcripts, and by categorizing and re-categorizing the interview data, I was increasing my understanding of Asperger's and synthesizing the material to be included in my thesis.

A second way of formally analyzing the interview data was to consider each interview separately and to attempt to perceive from the perspective of the interviewee. Each participant had a unique understanding of Asperger's and by attempting to assimilate his or her understanding, I was broadening my concept of Asperger's and adding depth to the description of Asperger's that I was able to relate. I was also able to conceive of different ways of making meaning out of Asperger's for someone who has been given the label, for someone who's child has been given the label, for someone who works intensely, one-to-one with people with Asperger's attempting to help them learn, and for someone who has to consider long-range programming and the overall picture for adolescents with Asperger's. By considering the perspective of each interviewee, I was able to make speculations about the experiences and emotions that lay behind his or her interview statements. Analyzing each interview for meaning broadened my overall understanding of Asperger's.

Writing the Thesis

Other Sources of Data

The eight interviews that I conducted were the main source of data for this thesis. I did, however, obtain ideas and data from other sources. I have read extensively about autism and Asperger's syndrome and as I have been reading I have been able to contrast and compare what the participants mentioned in their interviews with what the research reports have found about autism and Asperger's. In addition, I have the daily journal that I kept as I was working with Martin during the 1994/95 school year. I wrote this journal so that I could share daily happenings and my impressions of them with the school psychologist who was Martin's case manager. During the 1994/95 school year I met with this school psychologist weekly or bi-weekly to discuss my journal entries and his impressions of the case. These regular meetings aided my understanding of Martin and of Asperger's syndrome. In addition, I have an entire year of observation of adolescents with Asperger's and of individuals who work with them from my employment as a teacher aid in the Autism Program. During this two year time period I have also written another university paper about Asperger's syndrome and planned a presentation about the disorder. All of these activities have honed my understanding of Asperger's and prepared me to write this thesis.

Triangulation of Data

The many sources of data for this thesis ensure its validity. The eight interviews, the lengthy period of personal observation in the Autism Program, the journaling of my time with Martin, the thesis journal that I have kept, meetings to discuss the data, and analysis of the differences and similarities between the interviews and of the perspective of each interviewee

provide checks and counter-checks for the accuracy of the data. I have used triangulation as I have gathered data for this thesis. Stake (1994) defines triangulation as "a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation" (p. 241). I will also continue to use triangulation as I synthesize all of my sources of data in the writing of this thesis.

Format and Process of Writing the Thesis Document

As I have written this thesis I have had to continually synthesize and analyze data. The first chapter is an introduction to Asperger's, where I have chosen to introduce each of the eight participants and myself, by giving a sample of our interpretations of Asperger's. The second chapter describes the background for this study. I have given a literature review of the research history of Asperger's syndrome, a description of my personal involvement with Asperger's, and a rationale for writing a qualitative study investigating personal interaction plans for adolescents with Asperger's syndrome. In this present chapter I have described how I have gone about conducting this research. In the following chapter I plan to analyze my research data by synthesizing interview data, research data from the literature, and my interpretations of research data. In the final chapter, I will conclude the thesis by summarizing what I have learned about Asperger's syndrome and personal interaction plans for adolescents with Asperger's. It is my intention to produce a document that will allow readers to vicariously experience life with Asperger's and that comprehensively explains how others make meaning out of the disorder, so that they can make naturalistic generalizations and come to their own understandings of Asperger's. By integrating and analyzing current research theory on Asperger's syndrome with qualitative descriptions of life with Asperger's from nine perspectives, I intend to add depth to

the understanding of Asperger's and provide a route to social interaction for those with Asperger's syndrome.

DATA ANALYSIS AND DISCUSSION

Structure for Data Analysis and Discussion

I organized the data analysis by categorizing the data into statements that described Asperger's syndrome and statements that described social interaction treatment plans for individuals with Asperger's syndrome. I further categorized statements that described Asperger's syndrome into statements that matched the DSM-IV diagnostic criteria for Asperger's syndrome, statements that differed from the DSM-IV diagnostic criteria for Asperger's syndrome, and statements that seemed to be unique and did not relate to the DSM-IV diagnostic criteria for Asperger's syndrome. As I analyzed the data that described social interaction treatment plans for individuals with Asperger's syndrome, I recognized themes and I synthesized data into these themes. This chapter is written and organized around the structure that I used to analyze the data. The first section pertains to the participants' understanding of Asperger's syndrome, while the second section pertains to the participants' ideas about how to facilitate social interaction for individuals with Asperger's syndrome. Within each section, I incorporated a discussion which reflected my analysis of the perception of each participant, my analysis of related research literature, and my personal experience as researcher.

Describing Asperger's Syndrome

Qualitative Impairment in Social Interaction

Overview of Social Interaction Impairment

Asperger (1944/1991) called the disorder that he was describing autistic psychopathy because it caused such severe problems with social integration that afflicted individuals were best described as being isolated within themselves, cut off from the world. Each of the participants

noticed that some sort of barrier prevented social interaction for those with Asperger's. Teacher A described a sense that there is a plastic overlay acting as a transparent barrier to the world, stopping intuitive human connection. Adult A interpreted having Asperger's syndrome as being isolated from the world. When I asked him what having Asperger's syndrome meant to him he said: *"I used to think that it meant you basically were shunned, you didn't have much hope for a normal life."*

Sensing the Barrier

For Teacher A and I sensing the barrier is part of a qualitative diagnosis of Asperger's syndrome. Although I had never heard of Asperger's syndrome in the 1980s, I recognized that something was blocking intuitive, human connection with John, my Grade 5 student. Certainly, Teacher A uses her perception of what she calls *the shell* or the *plastic blanket* to recognize someone with Asperger's syndrome. Teacher A and I had the following conversation about intuitively sensing a barrier in someone with Asperger's.

I: In thinking back, were there any other students that you ever encountered that now, you think would fit in the Asperger's category?

TA: I can't remember specific students, but I would bet anything. You know I've been teaching for a long time. Before, in going back to the seventies in the regular stream. And kids who you could sense a difference but you didn't know quite what it was. I'm sure some of them.

I: Actually that's when my first interest in Asperger's came, when I taught a student and I couldn't quite place what was wrong.

TA: When you don't know the diagnosis or the descriptive stuff, you just intuitively

knew something wasn't there. And I think you sense the shell more than anything. And that kind of absence.

They Don't Invite

Other participants, such as Speech and Language Pathologist A, recognize that they are not being invited into a relationship or a personal communication by individuals with Asperger's. Speech and Language Pathologist A states: *"They don't invite. They don't invite people to be warm to them. Or to like them."*

There are subtle ways that people indicate interest and involvement with those to whom they are relating. A warm, lively gaze is one such indication of interest. Asperger recognized that the children he was describing did not use the nonverbal aspects of communication to add meaning to their words. Instead, their nonverbal communications were absent, poorly timed, or inappropriate to the conversation or social situation. Asperger's (1944/1991) description of what is lacking in the nonverbal communication of children with autism explains why one would not feel invited to interact with them.

> The disturbance is particularly clear when they are in conversation with others. Glance does not meet glance as it does when unity of conversational contact is established. When we talk to someone we do not only 'answer' with words, but we 'answer' with our look, our tone of voice, and the whole expressive play of face and hands. A large part of social relationships is conducted through eye gaze, but such relationships are of no interest to the autistic child. (p. 69)

Teacher A perceives how painful this failure to connect in social interactions is for adolescents and adults with Asperger's, noting the problems that Frank, David, and Adult A have in social

interactions. She says: *"They just don't connect in a normal kind of way. They have the same needs. And the brighter they are, the higher the functioning, the more painful it is."* When children with Asperger's do not show an interest in relating to their parents, their parents may be profoundly hurt. Parent A described how Martin, as a toddler, did not seem to want to please his parents.

> *Also, before he was three, he was different than his sister [sic], in that, as a young baby, as an early walker and a toddler, he didn't do things to please us. If we would be excited because he had bounced a ball or done anything, he wouldn't necessarily repeat it because he was pleased by our reaction.*

They Lack Social Intuition

Another way that some of the participants have of understanding the impairment in social interaction of people with Asperger's syndrome is to consider that they lack social intuition. People with Asperger's syndrome do not seem to have any social sense. Teacher Assistant A described how Frank was continually asking her about what she considered common-place social situations.

> *Frank* [sic] *was checking with me quite a bit about what I thought. Things that were kind of ordinary. What I thought was ordinary.*
>
> *"What would you do in this situation?" or "What do you think of this situation?"*
>
> *And some of it would involve children. For instance, "Would they be allowed to watch this show on T.V.?" or "Would their parents allow them?"*
>
> *Just kind of ordinary things like that.*
>
> *And then he was unsure of himself. Like, at work, "Do you think he likes me?" or*

"Do you think this?"

Like he couldn't seem to read other people.

Speech and Language Pathologist A says that individuals with Asperger's do not understand the subtle rules of social interactions. She explains: "*The timing in the reading of a social situation may be slightly off, may be half a beat off, but that's enough to exclude them from social situations.*" She explains why, as Teacher A describes it, David *just kind of misses the boat* and is unable to sustain appropriate social interactions so that he can maintain friendships with his peers:

> *He hasn't read the cues properly. He's misread/interpreted the cues. He's misinterpreted the messages. So he's probably entered a verbal repartee in the situation at the wrong time, or said the wrong thing, because he didn't comprehend the gist of what was going on. And I think lacking peer culture.*

An inability to read social situations can lead individuals with Asperger's into situations where they are ridiculed. David's handstand in the library is a good example of a poor choice of social behaviour. Teacher B describes what happens to David and other adolescents with Asperger's when they try to survive in the regular social world: "*They walk into situations that are so common place to regular students and they don't know how to read the situation. They become laughing stocks and in some cases, sort of the class clown.*" Basically, individuals with Asperger's syndrome have a great deal of difficulty in reading social cues. They lack social intuition and, therefore, they are often unable to interact in a meaningful, reciprocal fashion.

Asperger's theory that individuals with autism have a "disturbance of lively relationship with the whole environment" (1944/1991, p. 74) can be used to explain the inability of those with

Asperger's syndrome to relate to people in social situations. It can also be seen as a crucial grounding for current psychological theories about autism. Hobson (1993) believes that the inability of autistic children to relate to other people is the basis of their lack of understanding of other people's minds. Frith (1989) and Happé (1995) use relevance theory to explain why those with autism do not seem to attend to the intended message of a communication, hypothesizing that they do not organize and discard information according to how relevant it is to understanding. Processing information for meaning allows most people to interpret subtle aspects of communication, such as facial expression, tone of voice, inflection, and hand movements, as components of the intended message of the speaker. If someone with autism is unable to synthesize all of the relevant aspects of a communication into a meaningful whole, he or she is unable to understand the purpose of the communication. Subtle intended messages, such as irony or sarcasm, are lost. The ability to "read" the thoughts, feelings, and intentions of other human beings is absent, making social interaction very difficult. Teacher Assistant A states, "*I think it's an emotional disability.*" A "disturbance of lively relationship with the whole environment" is evident.

Restricted Repetitive and Stereotyped Patterns of Behaviour, Interests and Activities

The focus on obscure details, on a narrow field of interest, and on an egocentric reference to the world all seem to be aspects what Asperger described as an inability to relate to the whole environment. Individuals with Asperger's syndrome do have a very autistic frame of reference. This may be expressed by a concentration on a very narrow field of interest to the exclusion of all else. David and Jane spent a great deal of time concentrating on their respective talents and interests in art and track and field. Frank and Nancy would introduce their respective

perseverative topics, revolving around hockey and wrestling, men in uniform and violence, to any person who was willing to listen in any sort of social context. The egocentric frame of reference can also be expressed by an absolute concentration on a personal agenda. I found that it was extremely difficult to extract Martin from his intended plan for the day. Being unable to move out of an egocentric frame of reference also seems to be a way of defining Asperger's syndrome for some of the participants.

Martin's mother, Parent A, found that Martin's single-mindedness and his refusal to move from his own agenda were the aspects of his personality that best fit a diagnosis of Asperger's syndrome. She made the following references to his egocentricity:

He's wrapped up in himself so completely.

He doesn't have the sense of how he could moderate his behaviour for those he is living with.

This kid has a different mind set, he thinks differently.

Our conversation about what Asperger's meant in terms of her son went like this:

I: What parts of the diagnosis really fit for you? What makes sense in terms of Martin [sic]*?*

PA: The concept of his own schema, his own view of the world, that we all seem to be powerless to change. His view of the world is so singularly oriented to himself that no amount of support from anyone over any period of time seems to have changed that.

Teacher A noticed that Frank had the same sort of absolute concentration on his own agenda. She labelled this phenomenon *mental adrenalin* and related an episode, where Frank was absolutely determined to leave his place of residence, and there was no hope of dissuading him

despite possible dire consequences.

> *So, Frank* [sic] *just* (Snaps her fingers) *made up his mind that was it. He wasn't ever going back there. It was Christmas holidays. The worker had no other place for him. Nothing was set up. Frank just like a fish grabbing hold of something, he was leaving town. And he did, and I helped him escape!*
>
> *He phoned me and said, "I'm not going back to Shelly* [sic] *and Pete's* [sic]."
>
> *I mean it was like he had a glass bowl on. He just knew he could not stay in that situation. And he was going into this new situation which was pretty frightening for an eighteen-year-old, to pack his bags, take a bus to Saskatoon* [sic]. *He had no money. (I lent him the money.) And he had no place to come back to. And yet he was so . . . driven with it. Just so focused on it.*
>
> *I mean it all happened within hours. And I picked him up at their house. He packed a bag. She suspected something, and he was clever enough to throw her off track, saying he was just going to sleep overnight.*
>
> *You know, it was really interesting to watch him. The difference between his plans and a kid who maybe didn't have Asperger's was that he was so focused. It was just going to succeed, no matter what. You could just sort of envision him flying through the air and knocking everything . . . . You know, he was just sort of oblivious to the rest of the universe. Get to where he was going and it didn't matter how frightening or potentially frightening the situation was or anything else. It's almost like mental adrenalin.*

Teacher Assistant A also noticed Frank's egocentric concentration on his own agenda. She

described him as being wrapped up in himself, saying: *"He never really chatted in the hallways. He was sort of zooming in and zooming out and just doing his own/sort of living in his own world, his own timetable."*

This autistic orientation can seen in the interviews that I conducted with Adolescent A and Adult A. I found that it was difficult to interview Adolescent A. He did not seem to understand what I was asking him. I had to rephrase questions and make them very concrete, so that he would answer them. Even so, he tended to turn the conversation to his favourite topics. He said that he had a story to tell and he asked if he could tell a joke. He did not seem to understand the interview process. The interview was particularly difficult at the beginning, when I was trying to get him to explain what having Asperger's meant to him. Here is how he resisted my questions and attempted to divert the interview into his topics of interest:

I: *Some people have told you that you have Asperger's syndrome. How do you think that Asperger's syndrome affects you?*

Ad: *Not a heck of a lot.*

I: *Not a heck of a lot?*

Ad: *MmmmHmmm.*

I: *How would you be different if you didn't have it?*

Ad: *That's a hard question.*

I: *Yeah, I'm going to ask you some hard questions that you need to do some thinking for.*

Ad: *How would I be different? I don't know because I haven't known anything different.*

I: *You don't have any guesses how you would be different?*

Ad: *Not really. Cause I've never even thought about it.*

I: *Well, if you think of it later on, tell me.*

Ad: *Yeah, I'm too busy thinking about partying, and all that stuff, to worry about stuff like that.*

I: *Are you?*

Ad: *Yeah.*

I: *If someone asks you what Asperger's syndrome means, what do you tell them?*

Ad: *I really don't know. It seems to be some kind of clinical name tag.*

I: *MmmmHmmm. O.K. What does it mean to you?*

AdA: *What does it mean to me? Ha Ha. I've got a story that is a bit more soulful.*

Although I found the interview with Adult A to be less difficult than that with Adolescent A, I also thought he tended to miss the point of some of my questions. From time-to-time Adult A seemed to be giving pat, rehearsed answers. When I asked Adult A what Asperger's meant to him he gave me the very understandable answer: *"I used to think that it meant you basically were shunned, you didn't have much hope for a normal life"*, but then he went on to give a long oration about the position of those with autism in society and government funding for special needs programming:

A: *And I realize now that that's different, and I think people are getting more accepting of that now. Still have many grounds, many gains to make, though. Society in general does not have enough insight into people with Asperger's syndrome. And even with people with autism in general. People with disabilities are/how should I say*

it?/they're cast beneath the cracks by society, if they chose to let themselves be, or if they don't have enough people supporting them.

I: *MmmmHmmm. But, you think it's getting better?*

A: *Little bits, by little bits, it is. The only problem, the only problem right now, and actually what is getting worse, is government funding for special needs programs is being reduced all the time. And that makes it tougher to spread the message. We are having to find more creative ways in which to do that. Because, unfortunately, we do not have a lot of say in what the government does, as you can see. Basically, you elect them, and then, well, it doesn't really matter once they get in, they just do what they want. And that's a sad fact.*

I think Adult A misinterpreted a question that I asked about interactions as an adult and that he thought I was asking about dating situations or sexual relationships. Adult A looked embarrassed and uncomfortable during this sequence of our interview:

I: *When you/today, as an adult, what do you still use that you learned in the program, or mabe from Teacher B* [sic], *about interacting with others?*

A: *Would you repeat that again?*

I: *Like now, as an adult, ummm, when you are going to interact with someone else, what do you use that you learned?*

A: *My charm.* (Laughs)

I: (Laughs)

A: *Hopefully my charisma.*

I: *O.K.* (Laughs)

A: *Assuming I have any.*

I: *That was an embarrassing question. Ummm.*

A: *Yeah, that was. I was caught unaware.*

I: *MmmmHmmm.*

A: *So.*

I: *Well, if you were/say if you were planning/you wanted to do something with someone. What would you do? Like would you plan it to be an event, and you'd go somewhere and do something?*

A: (Laughs) *That was another one.*

At this point, I tried one more time to ask him about initiating social interactions, and Adult A replied by talking about the difficulty he has with dating. I surmised that he thought I was talking about dating all along, when I just wanted to know about his general interactions with other people. The process of interviewing both Adolescent A and Adult A was complicated by their difficulties in understanding the meaning of my questions and by their egocentric frame of reference.

Impairment in Social, Occupational, or Other Important Areas of Functioning

There are severe impairments in social and occupational functioning for the individuals with Asperger's syndrome who I have described in this paper. I have already detailed the great deal of difficulty that adolescents and adults with Asperger's have in initiating and maintaining friendships. The participants in this study agreed that not having friends is a common problem for adolescents with Asperger's syndrome. Adult A desperately wants to start dating, a normal desire for a twenty-three-year-old man, and yet he admits that he does not know how. Adult A

cannot date because he has difficulty initiating and maintaining a friendship and he lacks key social interaction skills. Not having friends is a severe impairment of social functioning for any human being. It is especially devastating in adolescence and early adulthood, when there is a strong desire for peer relationships.

No Significant General Delay in Language

Participants Disagree with DSM-IV Criterion

There was serious disagreement by the participants with the fourth criterion of Asperger's syndrome in the DSM-IV, "(d) There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years) (American Psychiatric Association, 1994, p. 77). Like researchers and clinicians, beginning with Hans Asperger, the participants have noticed difficulties in language development in individuals with Asperger's. There are two aspects to this disagreement with the lack of language delay criterion listed in the DSM-IV. In some cases individuals who are now diagnosed as having Asperger's syndrome did not speak by age 3 years. The other aspect of the disagreement deals with the use of language to communicate. Although individuals with Asperger's may have spoken by age 3, they may not have been using language for meaningful communication. Participants point out that individuals with Asperger's continue to have difficulty using and understanding the subtleties of meaning in language.

Individuals Diagnosed With Asperger's May Have Had Delayed Speech Development

When Wing (1981) developed a clinical description for Asperger's syndrome she noticed that slightly less than half of the children that she described as having Asperger's syndrome were slow to talk. Frith (1991) allows for both slow language development and odd language usage in

her definition of Asperger's, stating: "Perhaps the main feature of children for whom we propose the label Asperger syndrome is that they tend to speak fluently by the time they are five, even if their language development was slow to begin with, and even if their language is noticeably odd in its use for communication. Some of these children show dramatic improvements despite having had severe autistic symptoms as toddlers" (p. 3). One would suppose that children, such as those reported by Bowman (1988), Gillberg (1991), and Wing (1991), diagnosed in early childhood as autistic, and then re-diagnosed as having Asperger's syndrome at a later stage of development had little or no language as toddlers. Parent B recalls that language, as well as all other aspects of her daughter's early development, was delayed and that, when Jane did begin to speak, she would only speak to Parent B. Only one of the four children, who Asperger (1944/1991) used as case studies to represent autism, actually spoke before he talked. Early language development does not appear to be a set criterion for Asperger's syndrome.

Difficulties With Using Language for Communication

Speech and Language Pathologist A best described the reservations that people, who have had experience with Asperger's syndrome, have about a criterion that states that there is no clinically significant general delay in language. She emphasizes that the communication deficit of those with Asperger's should be addressed in diagnostic criteria:

> *I want people to understand that when they read in DSM-IV, that Asperger's has that language development, that that doesn't mean that they have adequate communication development. Because communication, I really do feel, is one of their big deficits. When you look at comprehending language, not in relation to word-word-word, but words in relation to each other, I think they do have difficulties.*

Some of the difficulties that people with Asperger's have with communication have been described under the heading Qualitative Impairment in Social Interaction in this paper. Speech and Language Pathologist A gave the following examples of the difficulties with communication that she saw in the language of the her first client with Asperger's syndrome:

> *He interpreted riddles, or jokes, very literally. He intellectualized them. I mean, he would analyze jokes, rather than understand them by their context.*
>
> *He had difficulty with using figurative language and with metaphors.*
>
> *When anything was concrete, he was fine at that. There was a huge gap, when it came to abstract language usage.*
>
> *He had to have one piece of information presented to him at a time.*
>
> *He didn't share personal information and he never used anything that was emotional type language. They have difficulty communicating feeling language.*
>
> *He just maintained his river of thought. You couldn't interrupt either. You couldn't interrupt him because he would lose the strand of his thinking or of what he had to say. It was that soap box kind of thing, the oratory type of language, as opposed to the give and take.*
>
> *And then there was that monotone quality, too. And there was just a lack of colour, as well, when he spoke.*

Although Asperger (1944/1991) emphasized the originality of the language of children with autism, he also asserted that the "contact-creating expressive functions are deficient in people with disturbed contact. If one listens carefully, one can invariably pick up these kinds of abnormalities in the language of autistic individuals, ..." (p. 70). In an attempt to explain what

is lacking in the language of someone with autism, Asperger (1944/1991) described what is usually expressed and interpreted in interpersonal communications:

> Language expresses interpersonal relationships as much as it provides objective information. Affect, for instance, can be directly expressed in language. We can hear from the tone of voice what relationship people have to each other, for instance superior and subordinate, and whether they are in sympathy or antipathy. This is regardless of the often deceptive content of the words themselves. It is this aspect of language which tell us what someone really thinks. In this way the perceptive listener can get behind the mask. He can tell from an individual's expressions what is lie and truth, what are empty words and what is genuinely meant. (p. 69)

It is exactly the perception of the communicated message that individuals with Asperger's have difficulty with. This is why researchers say they lack a theory of mind, they do not attend to what is relevant, and that they have a relational deficit. This is also why professionals who work with individuals with Asperger's, like Teacher A, notice, *"They just don't connect in a normal sort of way."* It is also why parents of children with Asperger's are hurt by their children's inability to do what most children seem to do naturally, learn what pleases and displeases their parents. It is also why individuals with Asperger's, such as Adult A feel shunned and alone. People with Asperger's syndrome have a great deal of difficulty reading the intended message and, therefore, perceiving what others are thinking or feeling. They do indeed have a deficit in the communication aspect of language.

No Significant Delay in Cognitive Development, Self-help Skills, Adaptive Behaviour, or Curiosity About the Environment

The fifth diagnostic criterion of the DSM-IV, "(e) There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than social interaction), and curiosity about the environment in childhood" (American Psychiatric Association, 1994, p. 77), is another DSM-IV diagnostic criterion that may not be exactly accurate for those with Asperger's. Some aspects of cognitive development may be delayed because children with Asperger's are not able to learn from relationships with other people and with the environment in the same way that non-autistic children can. In addition, an egocentric view of the world and an insistence on following one's own agenda may limit the learning of self-help skills and adaptive behaviours, such as grooming. Thirdly, curiosity about the environment may be limited to certain areas of interest.

Asperger (1944/1991) has a number of observations about the behaviour of young children with autistic psychopathy that seem to indicate a general delay in development. He comments that in early childhood the characteristics of autistic psychopathy are manifested by "difficulties in learning simple practical skills and in social adaptation" (p. 68). He also explains that the egocentric agenda of children with autism leads to conflicts in the home over basic life-skills and conflicts at school over learning the curriculum and following the rules of the classroom.

> In everything these children follow their own impulses and interests regardless of the outside world. In the family one can largely adjust to these peculiarities in order to avoid conflict, and simply let these children go their own way. Only when it comes to the daily

> chores of getting up, getting dressed, washing and eating do we get characteristic clashes. In school however, the freedom to indulge in spontaneous impulses and interest is heavily curtailed. Now the child is expected to sit still, pay attention and answer questions. (p. 78)

Asperger also describes stereotypic activity in young children with autistic psychopathy, noting that they may spend hours absorbed in "monotonous play with a shoelace" or "forming patterned rows with their toys" (p. 78). One would think that the autistic absorption in stereotypic activity or in following an egocentric agenda would limit cognitive development. Certainly Asperger's syndrome is considered a pervasive developmental disability.

Both of the parents of children with Asperger's syndrome, who I interviewed, noticed developmental delay in their children. Parent A noted general developmental delay in her daughter as a young child. Although Parent B was amazed by the verbal skills of her son, exaggerating to emphasize how unusually early he spoke: *"He was born talking!"*, she also described how difficult it was to teach him basic self-help skills. Martin's insistence on following his own agenda meant that he had not learned alphabetical order, or how to give change in monetary transactions. Encouraging Martin to eat healthy foods and to keep himself clean were constant struggles for his parents. Left to his own devices, Martin would eat a package of processed meat for lunch every day and wear the same pair of jeans for weeks at a time. Trying to change Martin's behaviour would usually result in extreme resistance and anger from Martin. Parent A explains the psychological stress that was involved in trying to live with Martin and teach him basic self-help skills:

> *Anyway, I don't know how to describe it other than high maintenance, the effort in terms*

of providing support to him for the most minute details of life, always having a dependent child and not seeing growth.

If things don't go well for him in the morning, if there isn't enough hot water, as he thinks he should have, or if somebody looks sideways at him, he's still very much involved in his own life. He doesn't have a sense of how he could moderate his behaviour for those he is living with. Living with someone like Martin [sic], *you just have to work all the time at reducing the moments of friction and anger, and it takes a lot of energy.*

Both Jane and Martin have extreme peaks and valleys in their academic and psychological profiles, indicating that they are developmentally delayed or impaired in some areas of cognitive functioning and also that they have cognitive strengths. Martin's mother, Parent A, reports the results of a series of academic tests that Martin was given in Grade 4, and their implications for diagnosis:

There was this profound unevenness in his skills and his knowledge, right up from Grade 4 to university level. Some skills were way below grade level.

For awhile we thought that it was a learning disability and his frustration with this unevenness and lack of integration. But things just never got better. They just always got worse and there was this predominant inability to read from social circumstances.

Jane's mother, Parent B, explains the areas of cognitive weakness that her eighteen-year-old daughter displays, despite being an excellent runner, a talented artist, and verbally articulate:

She has a lot of trouble interpreting her world. For example, she is just beginning to tell

time, and she doesn't even do it right all the time. And money, she's learning, but it's very slow. And she couldn't go and buy a car. She couldn't go and buy, well even a Slurpy or something like that. She would get very confused. She would have to be scripted to do that, and even then, if she got distracted it would be really hard. So the money, the time, dates. She doesn't seem to have a sense of whether things are a year in advance or two weeks in advance. It doesn't seem to mean anything to her. So I think she has some serious cognitive deficits, which don't help her communication.

The egocentric autism of individuals with Asperger's syndrome makes it difficulty for them to learn from other people or from the environment. Martin and Jane are both skilled verbally and yet they also both have profound academic weaknesses. Somehow they are not making the cognitive interpretations that lead to understanding of concepts like time and money. Asperger's syndrome seems to have caused a delay or an impairment in their cognitive development.

Criteria Not Met for Another PDD or Schizophrenia

As I have mentioned throughout this paper, the diagnosis of Asperger's syndrome is both controversial and difficult. Many aspects of Asperger's syndrome are identical to those of autism. Many symptoms of Asperger's syndrome are also seen in other disorders, such as: Obsessive-Compulsive Disorder, General Anxiety Disorder, Schizoid Personality Disorder, Childhood Schizophrenia, Attention Deficit Disorder, Mental Retardation, Developmental Language Disorder, Sematic-pragmatic Disorder, or Learning Disability. People who are diagnosed as having Asperger's syndrome have often had previous diagnoses, and there may be disagreement among clinicians and professionals as to whether the diagnosis of Asperger's syndrome is accurate when it is given. Neither Jane nor Martin were diagnosed as having

Asperger's syndrome until Grade 7. Prior to Grade 7, Jane had been labelled as having Obsessive Compulsive Disorder, and Martin had been diagnosed as having a personality disorder. The teachers in the Autism Program saw aspects of Martin's presentation that did not fit their picture of Asperger's syndrome. Learning Disabled and Attention Deficit Disorder were considered as more accurate labels for Martin. Differentiation of Asperger's syndrome from other disorders continues to be difficult throughout the life-time of individuals with Asperger's, as secondary symptoms may begin to cloud the clinical picture. Asperger's syndrome is indeed a controversial diagnosis.

Criteria Not Met For Another PDD

There is a great deal of confusion in differentiating Asperger's syndrome and autism. Although Asperger (1944/1991) mentioned stereotypic behaviour, such as rhythmic rocking, and described the child with autistic psychopathy being "like an alien, oblivious to the surrounding noise and movement, and inaccessible in his preoccupation" (p. 78), this picture of extreme autistic isolation is more typically thought of as Kanner's autism. Parent B explains her difficulty in understanding whether her daughter has Asperger's syndrome or autism:

> *I never really know whether to say Jane* [sic] *has Asperger's or autism. She has a lot of the characteristics of autistic people, but there are lots of those characteristics that she doesn't have. She didn't spin around as a child. Although, we've looked back in baby books now and noticed that we wrote, "Jane* [sic] *rocks back and forth in her bed."*

Speech and Language Pathologist A has her own intuitive way of recognizing people that she would categorize as having Asperger's syndrome. She thinks that Asperger's syndrome is a PDD and that it has features in common with autism, but that autism and Asperger's syndrome

are separate disorders. Generally, she perceives people with Asperger's as having right brain deficits and people with autism as having left brain deficits. She would not consider Jane as having Asperger's syndrome, even though that is Jane's present diagnosis, because Jane has excellent motor coordination, being a skilled athlete. She also intuitively believes that Temple Grandin has autism rather than Asperger's syndrome. In order for Speech and Language Pathologist A to categorize someone as having Asperger's syndrome, he or she would have to display:

poor motor-coordination

left brain strengths-being able to pick out the trees in the forest

right brain deficits-not being able to see the whole picture

poor timing in reading social situations

oratory-type speech-soap-box style

verbal strengths

intelligence

antagonistic qualities.

Teacher B has seen the diagnosis of the children he teaches change from Childhood Schizophrenia to autism to Asperger's syndrome. He says that he does not like to categorize his students, and that a label of Asperger's syndrome may actually be more detrimental than that of autism, because it brings with it the perception of ability and competence, when major support is required. However, if he were to define Asperger's syndrome, he would use degree of ability and degree of autism as criteria, stating:

I guess you see them as sort of a higher level, so that their skill level seems to be a notch

> *above all the others. And yet they still have the communication difficulties, and they still have the social, interactive difficulties, and the problem-solving difficulties. It just seems to be that they are more tuned in, and less autistic, less within themselves. So that's probably the greatest distinguishing factor.*

Teacher B's perception of Asperger's syndrome as a subtle form of autism, fits in with what many researchers (Gillberg & Gillberg, 1989; Szatmari, 1991; Tantam, 1991; Wing 1981, 1991) have reported.

Wing (1991) gives a refreshingly honest assessment of the chaos that has developed around diagnosing and differentiating autism and Asperger's syndrome. She believes that Asperger and Kanner were probably describing people with the same basic disability, but that there were slight differences in the populations that they chose to study and that each man presented his case studies with a slightly different emphasis. She gives an analogy from music to describe the resulting chaos in diagnosis and classification:

> It is as if some groups of people believe they are singing the same song but each singer has chosen a different key and some have changed their keys over time, while other groups are really singing the same song but each singer has called it by a different name. (p. 107)

Wing (1991) describes the difficulties of trying to fit children who are socially impaired into diagnostically acceptable categories. She describes the following problems in categorization:

> First, the longer the list of essential diagnostic criteria, the fewer the children that were eligible. Secondly, although it was possible to identify the diagnostic criteria when present in typical form, for every item there were problems of delimiting the borderlines.

> Thirdly, the criteria for different syndromes overlapped so much that some children could be given two or more diagnoses. Fourthly, many children had mixtures of features from different syndromes and could not be fitted precisely into any diagnostic category. The more narrowly the criteria were defined the fewer the children that could be included. (pp. 109-110)

Whether Asperger's syndrome should include all of the people within the autism spectrum who are presently verbal and attempt social interaction, or whether it should be limited to poorly coordinated, pedantic, intelligent, early talkers, who lack social intuition is perhaps a moot point. Both groups have a social interaction deficit that needs to be addressed. Perhaps the value of being given the diagnosis of Asperger's syndrome as opposed to that of autism should be considered. Teacher B believes that Asperger's syndrome may be a dangerous diagnosis because it leaves individuals without the supports that a diagnosis of autism may provide. Wing (1991) believes that the diagnosis of Asperger's syndrome is useful for two reasons. First, parents may more readily accept the diagnosis of Asperger's syndrome for their child than autism, since "autism is, in the minds of many lay people, synonymous with total absence of speech, social isolation, no eye contact, hyperactivity, agility and absorption in bodily stereotypies" (p. 117). Secondly, the recognition of Asperger's syndrome in adults has led to an understanding that autistic individuals of normal intelligence can be "undiagnosed in childhood but be referred to a psychiatrist in adult life" (p. 117). This has led to an awareness that untreatable mental illness may actually be Asperger's syndrome and also that the problems with living that are encountered by someone with a developmental disability may lead to psychological distress and possibly secondary mental illness. If a diagnosis of Asperger's

syndrome leads to treatment of social interaction deficits and an awareness of the autistic characteristics of the individual with the diagnosis, Asperger's syndrome is a useful diagnosis.

Criteria Not Met for Schizophrenia

Both Asperger and Kanner were clear in their differentiation of autism from Schizophrenia, stating that their clients with autism did not hallucinate, appeared abnormal from their earliest years, and showed improvement rather than deterioration (Happé, p. 11). Sula Wolff and her associates (Wolff & McGuire, 1995) link Asperger's syndrome and a disorder they have labelled schizoid personality disorder, noting the similarities in features between the two disorders. There is a historical, diagnostic link between Asperger's syndrome and Schizophrenia for the participants in this study, with Teacher B stating that over the years the diagnosis of the children he has taught has changed from Childhood Schizophrenia to Asperger's syndrome. Schizophrenia may have been the diagnosis that was given to these children before the mid 1940s, when Kanner and Asperger introduced autism to the world. Schizophrenia probably continued to be diagnosed for many years after 1944, for children who met Wing's (1981) "active but odd" criteria, and for previously undiagnosed adolescents and adults with Asperger's syndrome.

Differentiating Asperger's from Obsessive-Compulsive Disorder

A comment about the diagnosis of obsessive-compulsive disorder and Asperger's should be made here. Jane had been diagnosed as having Obsessive Compulsive Disorder prior to her diagnosis of Asperger's syndrome. Many individuals with Asperger's or autism do have perseverative thoughts, dwelling on their topics of interest to the exclusion of all else. Sometimes they may be able to go off into their own worlds so successfully that people believe

they are deaf. Parent B told me that this was true of Jane, who was actually tested for deafness. From my experience of working with Jane as a teacher assistant, I told her mother: *I can understand what they've been saying about her being deaf, because she seems to go away. When she gets something that she's thinking about or perseverating on, she's gone.* Parent A then explained how her daughter seems to be at war with the world, like Donna Williams:

> *And you can't get her back. And if you try to get her back, she gets angry. You know, because she's obviously thinking of something that's so important and so compelling to her that to get her back really is almost like invading her world.*
>
> *Donna Williams talks about her war with the world. And when I read her books, I really felt that that's the way Jane* [sic] *must feel, that she is at war with the world. And that world intrudes on her, in what she's doing and what she feels compelled to think. And it disturbs her and makes her angry. And so I can see why Donna Williams would call it her war with the world. That's exactly how Jane* [sic] *strikes me a lot of the time.*

People with Asperger's syndrome and autism want to think about their repetitive thoughts, unlike people with an obsessive-compulsive disorder. Perseverative, repetitive thoughts are part of their autism, part of why they seem isolated in their own worlds.

Other Suggested Diagnostic Criteria

The participants in my interviews mentioned several features that they use to identify individuals with Asperger's syndrome that were not mentioned in the DSM-IV diagnostic criteria. Teacher A used her ability to intuitively sense a barrier, as part of a qualitative diagnosis. Speech and Language Pathologist A has consistently noticed antagonistic qualities in individuals with Asperger's syndrome, and she wonders if this should be part of the diagnosis,

but she also links the antagonism with the frustration that people with Asperger's must feel. Teacher Assistant A, like Asperger (1994), noted malice in the behaviour of some individuals with Asperger's. Teacher B uses the inability to problem-solve as his number one criteria for diagnosing Asperger's syndrome. In this section I will address the presence of malice in individuals with Asperger's and the problem-solving deficit in those with Asperger's.

Malice as a Descriptive Criterion for Asperger's

One aspect of Asperger's (1944/1991) description of children with autistic psychopathy has not been repeated in the diagnostic criteria of other researchers and clinicians. Asperger interpreted some of the behaviour of his autistic children as being deliberately malicious and spiteful. He related the following description of Fritz, saying that his mischievous acts were characteristic of this type of child:

> The same boy who sat there listlessly with an absent look on his face would suddenly jump up with his eyes lit up, and before one could do anything, he would have done something mischievous. Perhaps he would knock everything off the table or bash another child. Of course he would always choose the smaller, more helpless ones to hit, who became very afraid of him. Perhaps he would turn on the lights or the water, or suddenly; run away from his mother or another accompanying adult, to be caught only with difficulty. Then again, he may have thrown himself into a puddle so that he would be spattered with mud from head to foot. These impulsive acts occurred without any warning and were therefore extremely difficult to manage or control. In each of these situations it was always the worst, most embarrassing, most dangerous thing that happened. The boy seemed to have a special sense for this, and yet he appeared to take

> hardly any notice of the world around him! No wonder the malicious behaviour of these children so often appears altogether 'calculated'. (p. 43)

Frith (1991) notes the discrepancy between Asperger's contention that these children were indifferent to the feelings of others and his belief that they would be deliberately malicious. She contends that Fritz may have been looking for a physical reaction to his behaviour, rather than a psychological one. She reports that Fritz readily admitted that he enjoyed seeing a display of anger on his teacher's face. Margaret Dewey (1991) has a similar explanation to Frith for apparently spiteful behaviour by autistic children. She views most of this behaviour as motivated by an interest in the physical reaction that results. Interestingly, Teacher Assistant A describes Frank as displaying cruel, malicious behaviour, but she also credits his motive as wanting to see a physical reaction.

Teacher Assistant A described how Frank would get into a mischievous kind of mood and do things to get people emotionally stirred up. She believed that he wanted to see people's emotional reaction, but that he was not aware of how they might feel. She described some of his behaviour as cruel and stated that he finally stopped this type of deliberate baiting, when an act of severe cruelty shocked everyone who learned of it, including authority figures, who were important to Frank. It seems that the malice that Asperger described and the cruelty that Teacher Assistant A detailed could be explained as an interest in a physical reaction rather than an act intended to illicit emotions.

Problem-Solving Deficit as a Descriptive Criterion for Asperger's

Teacher B uses the criterion of problem-solving ability to decide whether a student has Asperger's syndrome or not. He believes that someone would Asperger's would have a great deal of difficulty planning a project and then completing the project by putting all of the pieces together in the correct order to reach success. Teacher B explains:

> *They don't have the wherewithal to plan successfully. If left to their own devices, it's just never going to happen. They don't have the wherewithal to say, 'I have to set time lines for myself. I have to complete a, b, c, and then do d, e, f.' If someone came into a situation, and could take from step 1, and then follow through on all the steps to complete one of these activities, I would be very, very impressed. And one of my first inclinations would be to say, 'I question whether that person is Asperger's or not.'*

Teacher B also says that *"What they don't have is the ability to see how the small pieces fit together to make the whole."* Teacher B's observations about lack of planning ability for those with Asperger's syndrome would fit in with what researchers (Frith, 1991; Happé, 1995) are saying about the cognitive problems of people with autism and Asperger's. Relevance theory makes sense here. If one is unable to determine which pieces of information are relevant for meaning, one cannot synthesize and analyze and come up with an overall plan. Being able to pick out all of the details, but not being able to determine which details are important, leaves one direction less. Successful planning is impossible.

Treatment Plans for Adolescents With Asperger's Syndrome

Growth Through Relationships

Supportive, Loving Relationship Necessary

Despite the fact that Asperger's syndrome is characterised by an autistic frame of reference, relationships are mentioned by each of the participants as being crucial for the psychological health of adolescents with Asperger's syndrome. It appears that the best way to bring someone with Asperger's into the world, is in one-to-one caring relationships. A supportive, loving, one-to-one relationship can give the individual with Asperger's a healthy self-perception, a mentor for interpreting the social world, and a safe, secure base for making sense of the world. Individuals with Asperger's, like everyone else, benefit from a healthy sense of self. The social interaction deficit is profound in those with Asperger's, so having a trusted mentor to interpret social situations is crucial for growth in this area. In addition, people with Asperger's seem to have a great deal of difficulty with developing a meaningful structure for their lives. They seem to be compelled to perseverate on their topics of interest to find safety and to ground themselves. Caring, one-to-one relationships could provide an alternative safe, grounding place for individuals with Asperger's. A basic first step in developing treatment plans for adolescents with Asperger's syndrome is to provide each adolescent with one supportive, loving adult, who can develop an emotional and psychological growth-enhancing relationship with the adolescent.

Both of the participants with Asperger's mentioned other people as being key supports in their lives. When I asked Adolescent A what he thought of the Autism Program and how it had helped him, he mentioned the people that were involved:

I: *What do you think of the program?*

Ad: *Not too bad. The teachers are pretty good.*

I: *How does it help you?*

Ad: *How does it help?*

I: *MmmmHmmm.*

Ad: *Ah, it gives me somebody to talk to, laugh with.*

I: *MmmmHmmm. So you like the people in the program?*

Ad: *Yeah.*

I: *It gives you a place to go and people to talk to and laugh with.*

Adolescent A then when on to talk about Teacher Assistant A, who had been out of the school working with a student at a job experience sight. He expressed how he missed her.

Ad: *Yeah, particularly Teacher Assistant A* [sic], *which I don't really get to see much of anymore.*

I: *No. That's too bad. I know you really enjoy Teacher Assistant A.*

Ad: *Yeah.*

I: *Well, maybe after Patricia* [sic] *gets done her work program, Teacher Assistant A* [sic] *will be here more. Hope so. I miss her, too.*

Ad: *Yeah.*

I: *What would you like to change about the autism/Asperger's program?*

Ad: *I'd like to see Teacher Assistant A* [sic] *on a more regular basis.*

I think that Adolescent A was especially missing Teacher Assistant A because she provided him with the safe, secure, growth-enhancing relationship. Teacher Assistant A had had a close relationship with Adolescent A, where she had spent a great deal of time tutoring him on

a one-to-one basis, talking to him about social and emotional situations, and venturing into his perseverative world. Adolescent A had developed a whole cast of inter-galactic space travelling characters, who he thought about repetitively and who he built weapons for. He placed these characters in different situations and then made up stories about what was happening to them. Adolescent A was always looking for someone to go into this world with him and to help him decide how his characters would react in the situations he was imagining. Teacher Assistant A was willing to listen to him and to talk about how his characters might react emotionally. She explains how she believes Adolescent A wants someone he can trust to go into his world with him:

> *He wants someone else to make the connections with him, who has the experience of the world, history, society, politics, economics. He wants someone who has like a broad range, who is compassionate. Compassion is one of the most important words/positive words that he has. As well as forgiveness, generosity. And some of the words that are debilitation to him are money and greed.*
>
> *So, you know, he has the good and the evil in his stories. And he needs someone from the world that he can trust. And he doesn't know who he can trust. He really doesn't. Everyone has let him down in the basic relationships in his life. And he's been abused. He's been taken advantage of.*

I think that Teacher Assistant A was beginning to provide a basic, trusting relationship for Adolescent A, that he could use to enhance his sense of self and where he would feel safe to learn about social and emotional interactions.

Adult A relies on Teacher B to give him the support that he needs to get through life as an

adult with Asperger's. He regularly asks Teacher B for advice. For example, he told me that dating was something that he should talk to Teacher B about. Adult A recognizes that he needs support from someone like Teacher B, and he would advise adolescents with Asperger's to find someone like Teacher B to give them support. Adult A also recognizes the important role that Teacher B has played in his life, saying:

> *And Teacher B* [sic] *is more than just a teacher to me. He's more like a friend. And to tell you the truth, although I don't think I have ever told it to him, he is kind of like the Dad I never had. I mean I've gone over to his place. I've mowed his lawn for him. I've helped him clean the car. I mean, I've done things like that. I've gone on trips with him. I've done all those things like that that I missed in my childhood with my Dad. And Teacher B* [sic] *helped me fill part of that void. He made the difference in my life to where I am today.*

As well as providing a basic, caring relationship and social advice, Teacher B gives Adult A a structure for organizing his world. Adult A visits the Autism Program three or four times a week, helping with the flyer delivery route, using the classroom to do community college assignments, eating lunch with people in the program, and talking to Teacher B. This continued involvement with Teacher B and the Autism Program gives Adult A a place to go and a purpose for each day. Teacher Assistant A believes that Teacher B is a *"source of order and sanity"* for Adult A. He provides structure and an overall way of organizing life for Adult A.

Both Parent A and Parent B recognize the importance of caring, understanding people in the lives of their children. Parent A believes that relationships are key to her son's future. She explains what he needs:

> *Having a good relationship with him. I think that relationships are key to this, are key to him and his future. He works best with people who are willing to give, give, give, give, give. And if you can find people like that he will learn and mature from those relationships. I always thought his Grade 5 teacher really intuitively focused on Martin* [sic] *in terms of the relationship. She really offered him a lot of herself. And I think he did better as a result of that than if he had been in a special program.*

Parent B commends the people who have been caring and supportive of her daughter in the past. She is also well aware that her daughter will need energetic, loving people, who understand Asperger's syndrome and autism, supporting her for the rest of her life. Parent B has been working towards gathering such a network of people for her daughter. She believes that relationships with caring, understanding people are key for her daughter's future. As Jane's parent, she would like to provide such a network. *"I think the big thing that we're trying to do right now is to get people around Jane* [sic], *who care for her and who will be with her through her life."*

Parent B has recognized both the importance of relationships for her daughter and fact that a number of people have to be involved in such supportive, understanding relationships with her daughter. Parent B has acted as an advocate and as an interpreter of the world for her daughter throughout her life. However, she realizes that Jane needs other people to fill these roles. Parent B knows the physical and emotional strain that is involved in caring for a child with Asperger's. She acknowledges that neither she nor her husband are capable of dealing with the stress that is involved with living full time with Jane. Parent B knows that her daughter needs additional loving, supportive people to act as her advocates and social interpreters. A network of

people to fill these roles is necessary throughout Jane's life, today to relieve the strain on her parents and in the future to take their place.

A supportive network of care-givers seems to be key in providing the one-to-one relationships that those with Asperger's need. Parents and care-givers, who are continually providing support for those with Asperger's, need relief and emotional support. Teacher Assistant A has chosen to leave the Autism Program. Part of her decision to leave was based on the stress that she encountered in giving hours of one-to-one support to adolescents with Asperger's. One person should not have complete responsibility for filling the roles of mentor, interpreter, and advocate. The care-givers need relief and emotionally supportive relationships of their own in order to give the all-encompassing relational support that those with Asperger's need. I think that Parent B is correct in working to develop a supportive network for her daughter. The more people who understand Asperger's and who are willing to give of themselves in relationships with people with Asperger's, the better prognosis there is for individuals with Asperger's.

Healthy Self-Perception

Establishing a Relationship Key to Growth

Each of the participants in my study recognized relationships as key in the treatment of Asperger's syndrome. I have described how Adult A, Adolescent A, and Parents A and B value relationships in their own lives or in the lives of their children. Teachers A and B, Speech and Language Pathologist A, and Teacher Assistant A all spoke about establishing a relationship based on respect, unconditional acceptance, and affirmation as the basis for beginning to work with someone with Asperger's syndrome. Teacher A says that: *"You have to take a Humanist*

go over.

Teacher Assistant A perceived the need that people with Asperger's syndrome have for unconditional acceptance, and suggested that perhaps a pet would provide that love, without the complication of verbal communication:

> *There has to be some creature, something out there that just loves them whether they understand or not. That's easy to love, that it wouldn't be so hard to try and say the right thing. It seems that animals/find any animal, some animal that this person has some sort of bonding with.*

These four people, who have professional experience working with students with Asperger's syndrome, all recognize the value of establishing relationships with them based on unconditional acceptance, respect, and affirmation. Teacher Assistant A reported Frank's response to positive regard:

> *Frank* [sic] *just sparkled. If you paid just a little attention to Frank* [sic]. *It wouldn't take much encouragement. He just lapped it up. He needed that and it just made his day.*

Speech and Language Pathologist A advised Teacher B to give David a compliment a day, when Teacher B first began working with David, as a strategy for beginning to build a relationship with him. She laughed and commented in our interview, that Teacher B reported a few weeks later: *"Well, sometimes you have to give him two compliments a day."* Teacher A believes that once a trusting, respecting, valuing relationship has been established, she can begin to work with the individual with Asperger's. She explains the interdependence of validation, self-esteem, and trust:

> *To allow them to feel, you know, to validate their feelings and let them work them*

through. The most important thing is to let them develop self-esteem, and once that happens you can go. Most of them will do just about anything for me and they do it because they trust me.

Respecting Competence, Working Together Enhances Self-Esteem

The four school personnel found that treating students with Asperger's with respect, by valuing their competence, was another way of building the relationship. An activity where the school professional asked the individual with Asperger's for help or where they were simply two human beings working together, they thought was particularly beneficial for the self-esteem of the individual with Asperger's. Teacher A regards the episode where she and Adult A helped Frank leave town as one of the best social interactions that she has had with an individual with Asperger's syndrome because she and Adult A were equals, working together for a common goal. She explains why she thinks this social interaction was successful:

When we went on our adventure with Frank [sic] *there was a real sense of team work between us and a natural flow of things. He wasn't the student or the ex-student. We really worked well as a team and he felt very good. And there was a levelling, just down to two individuals. Do you know what I mean?*

I clarified what she meant and our conversation continued:

I: So, you're saying that why it worked well was because you had a common purpose?

TA: Yeah, a common purpose.

I: And you were on the same level.

TA: Yup. And there was a mutual respect for what the other one's role was. And it

was a role outside of school. You know. Yes, and there was a plan and a purpose. And I think that would be appropriate for any of the kids.

One of the strategies that Speech and Language Pathologist A uses to establish a good relationship with her clients with Asperger's syndrome is to ask for their advice. She asks for their advice and in doing so affirms their intelligence and competence. Speech and Language Pathologist A explains how she values her clients by asking for their help:

The other thing that I try to do is to get them to help me. So I'll say I have a difficulty in some area. And I tell them how smart they are. And I make sure that I tell them. A lot of it is like the Gentle Teaching Approach.

So, no matter how annoying they can be, I am constantly telling them how smart they are, and how valuable their skills are. And I'll ask them to help me out. 'Hey, I've got this difficulty. What do you think?'

Social interactions which have seemed to be successful for individuals with Asperger's have had mutual respect and a valuing of each other's competence as one of the components of the interaction. Speech and Language Pathologist A relates the story of when David met Temple Grandin, a university professor with Asperger's syndrome, who lecturers on autism, as an example of a successful social interaction. She said that Temple looked at his drawings and then they started chatting and comparing when they had first talked. Soon they were out of the meeting room together, photocopying David's art work. I told Speech and Language Pathologist A about Martin and David's first meeting, which had also seemed to be very successful, with both Martin and David doing voice imitations of movie characters and laughing. She and I discussed why these two particular social interactions were successful in our interview:

S: Why was it a success? I think it was because of her, and what she had to offer him. What he had to offer her was equal.

I: So it was a situation where it was possible to be equal.

S: Yeah!

I: They both had something to offer. It was reciprocal.

S: MmmmHmmm. I think what you saw with him and Martin [sic] *was the same.*

Being regarded as a competent human being, who can make a contribution is very important to Adult A. He talked about being taken out of one school, without an explanation, by his mother. He and I had the following conversation about this incident:

A: I don't know why she did. She never explained it to me.

I: So, you don't like things done to you.

A: I don't like things just done for me. Like if you are going to do something for me . . . . you know, you should tell me why because if you have got a logical reason for doing it, then most likely I'm going to accept it. She and I eventually talked that through. You know what that did? That took years.

I: But, it also sounds like a respect thing. You want people to treat you with respect.

A: Yeah.

I: That you are entitled to know why they are making this decision that is involving you and is crucial for your life.

A: Yes.

It seemed to me during the interview that Adult A was expressing his desire to be treated with respect as a competent human being. Adult A mentioned what he had accomplished for Teacher

B, such as cleaning his car and mowing his grass, when he was talking about the importance of Teacher B in his life. This seems to be another way of talking about wanting to be thought of as competent.

In addition Adult A talked about the value of field trips in his interview, stating that they were opportunities for bonding and that they put everyone on common ground. I asked him what he liked about field trips and he replied:

> *The stress, you got away from it all. You got a chance to bond a bit, which helped back at school. You get to know them. You get to know the routine. You understand each other, on a certain level. Because you are working together, and you just have to get along. And you find a way. You find a common ground. It helps, it always helps. It never hurts to have common ground.*

I interpreted common ground to mean a sense of equality, a place to meet each other and work together. I also interpreted Adult A as saying that he wants to be treated with respect as a competent human being, who is capable of making a contribution. Indeed, at one point in his interview, Adult A talks about helping out in the Autism Program, saying:

> *It's been important for me, and it's actually been very fulfilling for me that I can go and make a difference somewhere. And I need to make a difference. Wherever I go, whatever I do, I need to make a difference. If I don't feel that I can make a difference in something, then there is almost no point in me doing it.*

Respecting Autism as Part of Who They Are

Part of building a relationship with people with Asperger's syndrome is respecting their autism as part of who they are. Parent B believes that her daughter's psychological problems

could have been reduced if she had been given an earlier diagnosis and her parents and her teachers had understood how autism affected her behaviour. Since she did not receive a diagnosis of Asperger's syndrome until Grade 7, Jane has suffered through years of unrealistic expectations. Her mother explains how accepting autism as part of Jane's personality would have enhanced Jane's sense of self.

> *She has been pushed beyond what any person can be pushed and her self-concept has been eroded. So I figure, that's the key, is to maintain a good self-concept. Letting the person know that, yes they are autistic. This is the way they are. They can live a life that is worthwhile. But they don't have to be non-autistic, because they're never going to be non-autistic.*

I clarified her comments and she added to her explanation:

> *I: So valuing their autism as part of who they are?*
>
> *PB: That's right. That's what I would have done. That would have been the most important thing, I think, that an early diagnosis would have helped. If someone had said to me, 'You have this four-month-old child. She's going to have these problems. Work around it. Get help,' I could have done that. Do you know? And I think Jane* [sic] *would have been a much happier child. As long as the school and all the other places, that she interacted with, did it. Or if I could have explained it to them.*

When I asked Adult A what advice he would give to adolescents with Asperger's syndrome, he made a strong statement about accepting autism as part of who they are:

> *Don't deny. Don't deny the fact that you <u>have</u> a disability. For too long I tried to deny it because I was afraid of what it meant. Don't deny it, because when you deny it, then you*

try to deny who you are. That's the worst thing you can do. You have to be yourself.

Accepting and respecting individuals with Asperger's syndrome and autism for who they are is the message that Teacher B received from a speaker with Asperger's syndrome at a recent autism conference. Individuals with autism or Asperger's syndrome are beginning to act as self-advocates, promoting the culture of autism and telling non-autistic people not to expect those with autism to do all of the adjusting and changing. Teacher B quotes the speaker with Asperger's as saying:

> *'Accept us for who we are. And don't try to change us to meet your criteria. You may have to do some adjusting to make life pleasurable for both of us.'*

Teacher B accepts the message of respecting autism as part of the personality of people with Asperger's or autism, and he also accepts the responsibility of acting as their advocate. He gives his reactions to the speaker's comments endorsing a culture of autism:

> *I guess that's the key. We're not going to mold them into the type of individuals that we might wish that we could mold them into. I think that we've got to take what we've got and really accentuate the positive skills that they have. And try and bridge society's understanding of this population and just the general acceptance of these young men and women for who they are.*

Being in relationships with people who demonstrate respect for the autistic component of their personality and who act as advocates for them, would help those with Asperger's feel accepted for who they are. Such relationships could be a safe base for social growth.

Mentor for Interpreting the Social World

Once a safe, trusting relationship has been established with an adolescent with Asperger's

syndrome that relationship can be used as a place to observe, interpret, practice, and get feedback for social interactions. Since social interactions are extremely difficult for individuals with Asperger's to understand, they need the support of a mentor to interpret the social world. This mentor has to be someone they feel safe enough with to trust in this, their most vulnerable area. It also has to be someone who may accompany them into whatever social context they find themselves in, so that the mentor may observe what happens and be able to give support, feedback and suggestions.

Parents may act as their children's mentors in many social situations. Parent B found herself interpreting the world to her daughter because that is what her daughter seemed to need. In our interview, I stated that it was as though her daughter was using her as a social security blanket. Parent B agreed:

> *That's right. And also I interpreted her to the world. When people would come over she would sit near me. For example, we would be at the dinner table and she would ask me what this one was saying, what they meant by what they were saying. It was always what they meant by what they were saying. And were they talking about her? And so I was always taking Jane* [sic] *out when we had company in order to try to explain to her, try to reassure her that everything was okay, and that people weren't laughing at her, and that this was just the way that people interacted.*

Speech and Language Pathologist A reports that David's mother has been a mentor for him for most of his life. However, now she is finding that he does not want her to be a part of his social interactions as an adolescent, and she is unable to help him in many social situations.

David needs to accept a replacement for his mother as his social mentor. Speech and

Language Pathologist A is able to give David some social interaction suggestions, but she cannot enter many social interaction situations with him, so she is limited in the support she can give. Ideally, Speech and Language Pathologist A would like to observe social interactions and take note of the skills that David lacks. Then she would have a basis for teaching skills. Since she cannot do this, she attempts to help David in social interactions by making suggestions about how he could enter a social situation and by reviewing incidents that she knows about with him. Unfortunately, unless David accepts someone who could act as a social mentor into his interactions with his peers, he will continue to find himself in unfortunate situations, like the library handstand incident.

A mentor who could enter social situations with an adolescent with Asperger's would be able make suggestions to ease the situation and also would have observed which interaction skills to teach. From a teacher's point of view, Teacher B has found camping experiences to be very beneficial for exactly this reason. He can observe his students with Asperger's in natural social interaction situations and plan teaching strategies for them. He answered my interview question about the most positive social interaction experience by saying:

> *I guess the most positive social interaction experience has always been the camping experiences, because in those situations you're with those individuals for twenty-four hours a day. So you get to test out some of the ideas that you've been bantering around throughout the year. And you get to create social situations, where you can sit back and be an observer, or you can be an active participant, and you can sort of lay some groundwork for future planning. So, as far as from a teacher's perspective that is the greatest.*

Since parents are able to accompany their children into social situations for many years, they may naturally develop social mentor skills, such as Parent B has described. Parent A and Parent B have found themselves scripting their children prior to entering social situations. By scripting they mean telling their children concrete details about the social activity, such as who is going to be there, how long it is going to be, what is going to happen, what the parents plan to do, and what alternatives the children may chose while they are there. Parent A explains how she and her husband prepare Martin for shopping excursions:

> *Trying to give him cues to help him where he needs help. He responds to cuing. And sort of setting the scene. When you're taking Martin* [sic] *into a store you need to prepare him for what is going to happen, and what his Dad needs to do and what he needs to accomplish. He does respond to that.*

Parent B has learned what to anticipate from her daughter from years of observation, so she helps prepare her for social interactions by giving her alternative behaviours to chose from that will avoid problems. Parent B gives the following example of scripting:

> *We know, for example, if there are little children there, that Jane* [sic] *might be jealous of the little children. And she might even say something before she leaves, you know, 'I hate little children. I don't want to do this with them.' Or whatever.*
>
> *Then we can say to her, "Well, if you don't want to do that, why don't you watch T.V.?' or 'Do you want to take a movie over to the people's house?' or 'Would you like to get a movie that maybe this kid in the family might like to watch with you?'*
>
> *She does Nintendo now. You know, 'If you want to get away, you can always go into your room and do Nintendo.'*

So what we try to do, is not box her in. That's one of the things.

I asked Parent B about giving Jane feedback after a social interaction and Parent B explained that Jane often begins to talk about the event herself, so that feedback naturally occurs. However, if Jane is disturbed by something that happened, particularly if she thinks that someone did not like her, her parents initiate the feedback.

Teacher A would advise parents to teach social interaction skills at home and to create a framework for their children with Asperger's syndrome to rely on in social situations. She explains:

> *I would tell them to use teaching social skills at home, to do that as much as they can from the time the kids are little, so that when they are in a situation, they have a script to fall back on. Not scripting to the extent that the more autistic kids have. But I mean it is a form of scripting. They have to have a frame of reference from which to make conversation. Give them a list. 'You could talk about this.' 'You could talk about that.' Let them know what the options are instead of just assuming that they are going to do what all kids do. Because they don't know what all kids do.*

One-to-one relationships with school personnel also offer the opportunity to practice social interaction skills with a trusted mentor. Teacher Assistant A values the opportunity for discussion of social issues that a safe relationship gives adolescents with Asperger's. She would advise, as a starting point for discussions, *"Bring them everywhere and talk about it. It gives you contexts."* Teacher Assistant A found that she naturally spent a great deal of time talking about feelings in the discussions she had with David, Frank, and Adolescent A, and she said, referring to Frank, *"I think it was important for him to know what feelings, you had to specify, it had to be*

very clear." Speech and Language Pathologist A tries to remedy the deficits she sees in the social interactions of those with Asperger's in her one-to-one language therapy sessions with them. She tries to improve their use of feeling language, use of reciprocal conversation strategies, and understanding of social interactions by:

> *I've learned to do a lot of paraphrasing. You know, reflecting back. And trying to rephrase what they are saying in feeling language.*
>
> *I might ask them to comment on what I've just said. So I try to build in reciprocal types of conversation and communication.*
>
> *Try to role-play the situation.*

Teacher Assistant A uses role-playing and trying to present the point of view of an adolescent girl to give Adolescent A some strategies to use when he is talking to a girl. She tries to give him an entry to conversation by having him think about:

> *What's appropriate?*
>
> *What do you talk to someone about?*
>
> *She might be interested in this.*
>
> *What's her life like?*
>
> *What do you know about her?*
>
> *What do you think young ladies might be doing?*

Teacher A sees her relationship with Frank as an opportunity for him to practice relating to an adult female. She says, *"I'm the only one he can practice some of his male/female things with. And it's safe to practice with me."* Thus, safe relationships offer the opportunity for adolescents with Asperger's to begin to practice many of the components of social interactions.

Base for Structuring the World

A safe, secure relationship with a trusted adult can provide the structure that is lacking in the life of someone with Asperger's syndrome. It seems that individuals with Asperger's syndrome have a great deal of difficulty with organizing the overall structure of their lives. According to Frith (1989) and Happé (1995) they do not organize and discard information according to how relevant it is for understanding. Ozonoff, Rogers, and Pennington (1991) found that both their subjects with High Functioning Autism and their subjects with Asperger's syndrome were deficient compared to controls at executive function tasks, which measured problem solving ability, such as the Wisconsin Card Sorting Test and the Tower of Hanoi. The inability to solve simple, everyday problems because of an inability to understand which details of the problem are relevant to its solution would indeed be debilitating. A trusted adult in their lives, who could act as an executive to organize the structure of daily, weekly, and monthly events, would indeed be a welcome relief for adolescents with Asperger's syndrome.

It appears that Teacher B acts as an executive in Adult A's life, helping him to place an organizing structure around what would otherwise be a chaos of details. Teacher Assistant A recognizes the executive role that Teacher B plays in Adult A's life, saying that Teacher B is a *"source of order and sanity"* for Adult A. Teacher Assistant A also recognizes that if people with Asperger's syndrome are unable to find caring, trustworthy adults to help them structure their lives, they will look for other sources of structure. For, example, she believes that the very ordered religion that Frank has chosen provides the organizing structure that he needs in his life now that he has graduated from the Autism Program:

And the religion that he chose is a very ordered religion. And he knows he won't be able

to count on myself, or Teacher B [sic], *or some of the other people that he's counted on for years. So he needs an ordered view of the world from somewhere else.*

In terms of morality, and emotions, and all that, who's going to tell him where the limits are [now that he's graduated]*? And I think it's his own inner wisdom to/you know, that fit for him* [choose an ordered religion to structure his life].

Teacher B asserts that unless someone provides structure for individuals with Asperger's syndrome, they cannot work, socialize, or learn about social interactions. He believes that the ideal work situation for someone with Asperger's syndrome is one in which he or she acts as an apprentice. In this way structure is provided in the work place and the individual with Asperger's can concentrate on the details of his or her job, without worrying about the overall direction of the work project. Teacher B explains:

I really see them as sort of ideal apprentice people. They have that desire to learn and the desire to sort of follow direction. What they don't have is the wherewithal to look at the big picture and see how the small pieces fit together to make the whole or to deal with the unknown or variables that may crop up.

Teacher B also believes that unless someone acts as a recreation director to organize the social outings of individuals with Asperger's syndrome, that they will sit at home, unable or unwilling to set up opportunities to meet with other people. Teacher B made the following statements about structuring social opportunities for individuals with Asperger's syndrome in his interview:

I think the one thing that I have learned, over the years, is that structure is essential. And if you think that <u>any</u> social development is going to arise in impromptu, off-the-cuff

activities or social engagements, it's just not going to happen.

I think in the long hall they're going to have to have people that can help them get into structured activities and support them there, so that there aren't the levels of down time that exist. Without planned, structured activities comes loneliness and all the other negatives that go with that.

I think that there is a need, from a very early age, to create social gatherings and social opportunities for these young men and women to interact, often with each other and ideal situations with regular peers. Things like games clubs, computer clubs, movie clubs, bowling leagues, and swimming clubs. Start at a very young age, and then continue. It's essential that they have these options when they are young adults.

Teacher B also asserts that opportunities for learning social interaction skills have to be planned and structured for adolescents with Asperger's syndrome. Casual, independent learning will not take place without concrete skills being taught in structured settings. Teacher B promotes the use of discussion groups as structured settings for adolescents with Asperger's syndrome to learn social interaction skills:

From a teaching perspective, resources like discussion circles are <u>essential</u>. They're not going to learn through the normal channels of observation and day-to-day interactions, because many of them opt out. They opt out because that's easiest for them, or they don't want to get caught up in the confusion of social interactions, or many of them opt out because of previous embarrassments, teasing, or bad memories. There are scars that have to be recognized and mended over time.

Adult A comments on the value of discussion groups in his interview, stating that he finds them to

very useful on Monday mornings, which I interpreted as meaning that they are especially needed after a weekend of coping with the social world on his own.

There has to be a format. And I think group discussions are always a good way, once in awhile.

When I was at Queens Collegiate [sic], *we had group discussions on Monday. Talked about our weekend. And I don't know if we are doing that as much here, any more.*

I think that Monday is better because you're just getting back in. It's a nice way to get settled in.

Teacher Assistant A concurs with Teacher B and Adult B, emphasizing the importance of structured activities for social interaction skills learning. She advises organizing:

Structured things, structured activities. Activities where there was a small group. Up to five kids. Somebody there directing things, trying to keep them focused on whatever it was they were focusing on, if they needed help directing conversation. But most of all a planned activity, a planned discussion.

Adolescents with Asperger's syndrome need help in organizing the overall structure of their lives in terms of work, recreation, and learning social interaction skills. A trusted adult, who could act as a life organizing executive would greatly enhance the quality of their lives by providing the safety and security of a structured environment. It appears that relationships with caring adults can provide the requirements for survival that those with Asperger's require: positive self-perception, interpretation of the social world, and a structure for organizing their lives. Loving, knowledgeable care-takers are key to successful treatment plans for adolescents

with Asperger's syndrome.

Growth Through Areas of Strength

Treatment Plans Should Involve Areas of Strength

A second crucial component of successful treatment plans for adolescents with Asperger's syndrome is to use their strengths as part of the treatment plans. There are two areas of strength that can be used to advantage in treatment plans for adolescents with Asperger's syndrome. The ability that those with Asperger's syndrome have to focus on details and to learn by observation can be used to advantage in treatment plans that involve social interactions skills and employment skills. Secondly, their areas of interest and in some cases their perseverations can be used to provide opportunities for social interaction and employment, and to give an overall organizing structure for their lives.

Visual Attention to Detail Used in Treatment Plans

One consistent strength that people with Asperger's syndrome display is their ability to pay attention to visual details. This strength could be used in social interaction treatment plans by teaching the adolescents with Asperger's what visual cues to look for as an indication of feelings or timing in a conversation. For example, rolling eyes may indicate disbelief and yawning may be a sign or boredom and a cue to end the conversation. Teacher Assistant A believes that Adult A is already skilled at picking up visual cues as to what pleases a person. She thinks he studies people to know how to act:

> *He really changes with different people. He always acts about the same with me. As soon as he gets to know a person he'll do things to please. He's always watching, watching their reactions.*

In his interview, Adult A talked about how he does use observation to learn about social interactions:

> *You see how other people interact, and you learn a lot by seeing how other people interact. I think that's generally how you learn some of the ropes, anyway. You see other people interact. And sometimes you make mistakes. You pick up on some negative stuff that people do. Then you pick up some positive. And I guess you just have to use judgement. You weed out things. You learn by watching. And sometimes you even learn by reading in the newspaper, because you see domestic incidences, all the time.*

Adult A has learned from his observations that people can be deceptive. He says: *"I exercise more critical thinking. I challenge. I mean, sometimes, people appear to be this and then they ain't. Sometimes you get burned."*

Adolescent A has also learned to use his observation skills to learn about people and social interactions. He gave me the strategy that he had shared with Martin for finding a girlfriend.

> *I basically told him, it's kind of like fishing. It's a pattern. It's a little process they do in order/like the fishing thing does like: fish, location, and presentation. So like studying the habits and sort of the person. Then there's location and then there's presentation.*

Adolescent A was telling Martin that you had to study the habits of girls to know how to approach them, and then you had to be in the right location, and present yourself to them in an acceptable manner.

Using intellect and attention to visual details could also be useful in learning the tasks of a work sight. Learning the required skills by careful observation, within the structure provided by an apprentice-like role at a work sight, would increase the chances of occupational success for an

individual with Asperger's.

Area of Interest Used in Treatment Plans

As has been stated earlier in this document, many individuals with Asperger's have an all consuming area of interest or perseveration. This interest can be used to advantage to provide a route to involvement with the world for those with Asperger's syndrome. Some of individuals with Asperger's in this study have begun to connect to the world through their perseverations.

David has an all consuming interest in art. His drawings have begun to give him an entry into social situations. For example, David showed Temple Grandin his sketch book as a way of introducing himself to her. David's artistic skill is an important component of who he is. It gives him a positive sense of self, an occupation for his time, and a way of being known. Speech and Language Pathologist A told me how David has used art throughout his life to improve his self-perception:

> *He told me that he would draw all the time when he was younger, because he was good at it. He said people thought he was stupid. And he said when he would draw, he would not feel stupid. It was something he was good at.*

Perhaps in time David could develop social relationships through his interest in art, or use art in an employment setting. Teacher Assistant A suggests how David's interest in art could be used in personal interaction treatment plans for David:

> *Always with something they love to do, like art. Send David* [sic] *to Banff to the School of Art with someone. Start slowly with maybe someone who has been there and have him talk to that person and then gradually, eventually, he would be able to go there. Introduce him slowly through someone he might feel comfortable with to other people*

who do art in the city. Go with their interests.

Although David has an area of interest and a talent that may give him entry to social and occupational situations, he still has a grave deficit in understanding social interactions. His antagonistic manner can easily sabotage social and work relationships. Giving the wrong message or not comprehending an intended message, could end his participation in social events or employment opportunities. He needs an adult who understands him and his autism, and who would be willing to act as an advocate and an interpreter, to accompany him to art related social activities and art related education and employment sights. David's acceptance of such a care person is dubious, but his entry into social interactions without an advocate and an interpreter has little chance of success. The possibility is high that he will be left drawing alone at home.

Jane's perseverative interest in and talent for running has provided her with some of the same benefits as art has for David. She has received acclaim and recognition for her athletic ability. It is part of who she is and it helps to structure her world. There is a sequence to training schedules and meets that gives organization to her days and weeks, and provides events on her calendar. However, her parents have discovered that it is extremely important that they be a part of her athletic events. They have found themselves interpreting autism and their daughter to coaches and other parents. They have had to anticipate their daughter's reactions to losing a race or being criticized by a coach, and to plan coping strategies for her. A component of Jane's success on the track is her parents' presence as interpreters and advocates. If they can recruit more people in Jane's running world, who understand her autism, her chances of continued success will multiply.

Parent B has come to the conclusion that advocacy for autism is one of the best ways of

aiding her daughter. Jane does best among people who understand her and who are knowledgeable about Asperger's syndrome and autism. Parent B described how difficult social situations are for her daughter when people misinterpret her behaviour because they do not understand autism, and talked about how she tries to prepare people for Jane:

PB: So every social situation is a nightmare with Jane [sic], *unless she's around people that she knows. One of the things that I do now is that I try to keep Jane* [sic] *around people that she knows and who understand autism. So I try not to get her into new situations and new people, unless the ground is very carefully prepared, because it often ends up being a disaster.*

I: So one thing you do now is scripting, before you go to a social event. And the other thing is being very carefully prepared.

PB: Yes.

I: If it's going to be any sort of a new situation, to prepare Jane [sic] *and to prepare the people.*

PB: The people who are at it. Oh, yes, we have to prepare the people, because they will say the darnedest things and they will do the darnedest things.

Some individuals with Asperger's syndrome or autism have begun to use their interest in and knowledge about autism as a way of organizing their lives. Temple Grandin is a good example of such a person. She travels around the world giving lectures about the topic she knows best: autism and how it affects her. Her lecture circuit gives her life structure and her interest in autism gives her an occupation and social contact. Teacher B interprets autism as the foundation of security in her life:

> *"She's made a career out of being who she is and learning, because to her that's the greatest foundation of security. 'I'm autistic, I can talk about autism, and I know my area of expertise.'*

Acting as an advocate for others with autism and Asperger's syndrome may also help Adult A structure his life and give him a sense of self-worth. He has spoken as a panellist at an autism conference and he mentions wanting to *make a difference* with his life. Adult A credits discovering his interest and aptitude for accounting as a turning point in his life, he calls it: *finding my niche.* Both acting as an advocate for people with Asperger's syndrome and autism and studying for a career in accounting, allow Adult A to use his areas of knowledge and interest to find structure and competence in the world. As Adult A says:

> *I found my niche. And I plan to pursue that, and . . . . basically keep doing the things where I can make a difference. And I feel that's where everybody, even a person who has special needs, you know, they all have a need to make a difference, somewhere. And basically, that's . . . . the bottom line, right there.*

CONCLUSION

Believing that one can make a difference and that one is a person of worth is a mark of psychological health. Adult A is striving to find a place for himself in the world that gives him a sense of competence. Parents, teachers, clinicians, and friends of adolescents with Asperger's syndrome would like to help them to achieve a place of worth in the world. The route to psychological health for adolescents with Asperger's involves finding a way to connect with the world as people of worth. The participants in this study have indicated that the key components of success for such a connection are: relationships, structure, and area of interest.

Relationships that provide safety and security can be used as a basis for enhancing self-perception, interpreting the social world, and providing a life-organizing structure. People who are willing to act as Humanists, basing their relationships with adolescents with Asperger's on respect, unconditional acceptance, and affirmation, are the key to successful treatment plans for adolescents with Asperger's syndrome. Care-givers who have established such relationships and who understand Asperger's syndrome can act as interpretive bridges between adolescents with Asperger's and the general population. In one-to-one situations the trusted care-giver may explain social interactions and model components of social interactions, such as entry skills, reciprocal conversation, and using visual cues to interpret feelings and thoughts. In social situations the trusted care-giver may act as a mentor, interpreting social interactions as they occur and encouraging appropriate social behaviour. A mentor may script social encounters prior to their occurrence and debrief afterwards. A committed care-giver may also act as an advocate, interpreting the behaviours of adolescents with Asperger's to the people they will encounter in each social situation. Finally, a trusted, understanding care-taker may act as an executive,

providing organization and structure in terms of recreation, occupation, and social interaction.

Providing structure appears to be a key component to successful treatment plans for adolescents with Asperger's syndrome. Because executive function, problem solving abilities are hampered by an inability to organize and discard information for meaning, individuals with Asperger's are at risk of being lost in a chaos of details. They need an outside agency to provide structure for their lives. Planned opportunities for recreation and social interaction are required so that individuals with Asperger's are not left alone and at risk for depression. A specific plan for practicing social interaction skills is required, with a experienced, understanding teacher to organize sequential, one-to-one lesson plans or to facilitate group discussions. An apprentice-like occupation, where someone else provides the long-term planning and structure for the work place seems to be ideal.

The area of interest or the perseveration of an adolescent with Asperger's syndrome may be used as a starting point to a social interaction treatment plan, and eventually to the overall goal of finding a place of belonging in the world. The area of interest may be used to as an opportunity to come into social contact with other people. For example, an individual with Asperger's, with the support of a mentor and advocate, may join a club or find an acquaintance with a similar interest. This would be an opportunity to begin to learn social interaction skills. Eventually the area of interest may become a way of placing structure on the world, an occupation, and a way to *make a difference.*

The crucial component to any treatment plan for adolescents with Asperger's syndrome seems to be loving, understanding people. A network of people who can and will act as mentors, social interpreters, life-executives, and advocates is required. Such a network could bridge the

barrier and bring life-enhancing access to the world for adolescents with Asperger's syndrome.

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Appendix A

Gillberg and Gillberg (1989) Definition of Asperger's Syndrome

Asperger syndrome was diagnosed in cases showing all of the following six symptoms:

1. Severe impairment in reciprocal social interaction, showing in (a) inability to interact or play reciprocally with age-peers, (b) a lack of normal desire to be in the company of age-peers, (c) a lack of appreciation of social cues, resulting in odd, socially or emotionally inappropriate behaviour, usually thought to reflect "coldness", "stiffness", "emotional bluntness/immaturity", "extreme egocentricity" or "(unintentional) play acting" (such as in the movies from the early period).

2. An all-absorbing, circumscribed interest in a subject, such as meteorology, astronomy or Greek history. This interest may change in content over the years, but its fundamental style remains in that it goes to extremes, excludes most other activities and is adhered to in a repetitive way and relies on rote memory rather than meaning and connection.

3. A stereotyped way of trying in introduce and impose routines or the particular interest in all or almost all aspects or ordinary life.

4. Speech and language problems showing as (a) delayed language development as compared with expected given the child's social language background, (b) superficially perfect expressive language with a strong tendency to become formal and pedantic and usually with a flat, staccato-like prosody, and (c) mild or moderate impairment of language comprehension with concrete misinterpretations of spoken language against a background of much better expressive language skills

5. Non-verbal communication problems, with limited or clumsy gestures and little or inappropriate facial expression.

6. Motor clumsiness was not a prerequisite for diagnosis of Asperger syndrome in a previous publication from this centre (Gillberg, 1988). However, as it turned out, almost all of the 23 children in that study were found to suffer from overall clumsiness on neurodevelopmental examination. We therefore decided to include it in our diagnostic definition of Asperger syndrome.

No requirements were imposed regarding the child's intellectual level.

Appendix B

Szatmari, Bremner, and Nagy (1989) Proposed Criteria for Asperger's Syndrome

1. Solitary:
   Two of:
      No close friends
      Avoids others
      No interest in making friends
      A loner

2. Impaired Social Interaction:
   One of:
      Approaches others only to have own needs met
      A clumsy social approach
      One-sided responses to peers
      Difficulty sensing feelings of others
      Detached from feelings of others

3. Impaired Nonverbal Communication:
   One of:
      Limited facial expression
      Unable to read emotion from facial expression of child
      Unable to give message with eyes
      Does not look at others
      Does not use hands to express oneself
      Gestures are large and clumsy
      Comes too close to others

4. Odd Speech:
   Two of:
      Abnormalities in inflection
      Talks too much
      Talks too little
      Lack of cohesion to conversation
      Idiosyncratic use of words
      Repetitive patterns of speech

5. Does Not Meet DSM-III Criteria for:
   Autistic disorder

Appendix C

ICD-10 (1992) Diagnostic Criteria for Asperger's Syndrome

1. A lack of any clinically significant general delay in language or cognitive development. Diagnosis requires that single words should have developed by two years of age or earlier and that communicative phrases be used by three years of age or earlier. Self-help skills, adaptive behaviour and curiosity about the environment during the first three years should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not a necessary feature). Isolated special skills, often related to abnormal preoccupations, are common, but are not required for diagnosis.

2. Qualitative impairments in reciprocal social interaction (criteria as for autism). Diagnosis requires demonstrable abnormalities in at least three out of the following five areas:

(a) failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction;

(b) failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interest, activities and emotions;

(c) rarely seeking and using other people for comfort and affection at times of stress or distress and/or offering comfort and affection to others when they are showing distress or unhappiness;

(d) lack of shared enjoyment in terms of vicarious pleasure in other people's happiness and/or a spontaneous seeking to share their own enjoyment through joint involvement with others;

(e) a lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; and/or lack of modulation of behaviour according to social context, and/or weak integration of social, emotional and communicative behaviours.

3. Restricted, repetitive, and stereotyped patterns of behaviour, interest and activities (Criteria as for autism; however it would be less usual for these to include either motor mannerisms or preoccupations with part-objects or non-functional elements of play materials). Diagnosis requires demonstrable abnormalities in at least two out of the following six areas:

(a) an encompassing preoccupation with stereotyped and restricted patterns of interest;

(b) specific attachments to unusual objects;

(c) apparently compulsive adherence to specific, non-functional, routines or rituals;

(d) stereotyped and repetitive motor mannerisms that involve either hand/finger flapping or twisting, or complex whole body movements;

(e) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise/vibration that they generate);

(f) distress over changes in small, non-functional, details of the environment.

Appendix D

Letter of Consent to Professionals and Parents

To Whom it May Concern,

I am requesting that you be a participant in a research study that I am conducting for the thesis requirements of a Master's of Education degree from the University of Manitoba. The purpose of the study is to investigate personal interaction plans in the treatment of adolescents with Asperger's syndrome. As a participant in the study, I will ask you to take part in an interview with me where we will discuss your experiences with individuals with Asperger's, your understanding of individual's with Asperger's, and your insights into the beneficial aspects of personal interaction plans for adolescents with Asperger's syndrome. The interview will be tape-recorded, and the data from the interview will be used in my thesis as anecdotes and as the basis for analysis.

If you do not want the interview to be tape-recorded, I will not proceed with the interview, and, unfortunately, I will not be able to include you as a participant in the study.

I anticipate that the interview will be from forty-five to sixty minutes long and that the two subsequent mini-interviews to discuss my interpretations of data from the interview will be about ten minutes long. The total time required for your participation in this study will be less than two hours.

Your personal information will be kept confidential during this study. I will not use your name or other identifying personal information about you in my data notes or in the thesis. Once the research is completed, I will erase the audio-tapes that I have made of the interview.

During the interview, you have the right to refuse to answer any questions. You also have the right to end the interview at any time and to opt out of the study at any time. You may also request to read a copy of the interview transcript, and portions of the interview will be deleted at your request. I intend to discuss my initial interpretations with you at a follow-up mini-interview. At this time, you will have the opportunity to revise your statements or to clarify your statements.

When the study is complete, I plan to send each participant a summary of the results of this research.

If you wish to obtain additional information about this study you may contact my thesis advisor, Dr. Riva Bartell, Faculty of Education, University of Manitoba, Winnipeg, Manitoba, R3T 2N2, Telephone ( ).

This research has been approved by the Faculty of Education Research and Ethics Committee, University of Manitoba.

First Paragraph of Letter of Consent for Individuals with Asperger's

I am requesting that you be a participant in a research study that I am conducting for the thesis requirements of a Master's of Education degree from the University of Manitoba. The purpose of the study is to investigate personal interaction plans in the treatment of adolescents with Asperger's syndrome. As a participant in the study, I will ask you to take part in an interview with me where we will discuss your experiences as an individual with Asperger's, your understanding of yourself and Asperger's, and your insights into how personal interaction plans could benefit you and adolescents with Asperger's syndrome. The interview will be tape-recorded, and the data from the interview will be used in my thesis as anecdotes and as the basis for analysis.

Consent Form

I, _____, agree to be interviewed as a participant in a study investigating personal interaction plans in the treatment of Asperger's syndrome, and I agree to have the data from the interview transcribed and utilized in a Master's of Education thesis in Education from the University of Manitoba.

I have read the attached information sheet on this study. I understand that the interview will be audio taped. I understand that I may refuse to answer any questions in the interview and that I may stop the interview at any time. I understand that I may review the interview transcript and request that I may request that a portion of the transcript or all of the transcript be omitted from the study. I also understand that I may opt out of the study at any time. I know that there will be two follow-up mini-interviews, where the interviewer will discuss her initial interpretations of the data from my interview and ask me for feedback on those interpretations.

Having read the attached information sheet, I understand that personal information about the participants will be kept confidential and that the audio-tapes will be erased at the end of the study.

_____ _____

Date Signature of Participant in ink

_____ _____

Date Signature of Researcher in ink

Appendix E

Interview Protocol for an Adolescent with Asperger's Syndrome

The following questions will form the basis of the interview.

1. Some people have told you that you have Asperger's syndrome. How do you think Asperger's syndrome affects you? How would you be different if you did not have Asperger's syndrome? If someone asks you what Asperger's syndrome is, what do you tell them? What does Asperger's syndrome mean to you? Can you explain what it means to have Asperger's by using a story about something that has happened to you because of Asperger's?

2. When did you first become aware that you were somehow different from most other people? How did you make sense out of that difference? When did someone first use the words Asperger's syndrome with you? What did that mean to you then? Can you tell me some stories about that time, when you were first thinking about what having Asperger's syndrome meant?

3. I am especially interested in what it is like to be a teenager with Asperger's. Do you think your life is different from that of other teenagers because you have Asperger's? How? How do you think your life is the same as that of every other teenager? Can you tell me about some of the things that have been happening to you lately? What parts of these happenings have to do with you having Asperger's?

4. How have things changed since you were a child? What do you think you have learned about yourself and Asperger's since you were a child? Can you tell me a story that would explain to me what it was like to be a child with Asperger's? Now can you tell me another story from your teenage years?

5. What would you like to say to other adolescents with Asperger's?

6. The school that you attend has a special program for students with Asperger's and students with autism. What do you think of that program? How is it helpful for you? What would you like to change about it? What have you learned from it?

7. Some experts say that it is hard for people with Asperger's syndrome to interact socially and that it is particularly difficult for people with Asperger's to have social interactions with people of the same age group. So the experts would say that you would have problems interacting with other teenagers. What do you think of that idea? Is it true for you? Can you give me some examples? What has been happening lately when you attempt to interact with another teenager? Can you explain? Is there a difference for you when the person that you are interacting with is an adult? How is it different?

8. If a teacher or another adult wanted to help a teenager with Asperger's establish a relationship with another teenager, what should the adult do? What helps you when you want to

spend time interacting with another teenager? What would you tell teachers definitely not to do? What advice would you have for other adolescents with Asperger's whom want to interact with their peers? When you are planning to spend time with another teenager, what do you think about before you get together with that person?

9. Now that we have been doing some talking about Asperger's syndrome, is there anything else that you would like to say? Have you thought of something while we have been talking? Do you have any questions for me? How would you sum up your thoughts and feelings about Asperger's syndrome?

Interview Protocol for Adult with Asperger's

The following questions will form the basis of the interview:

1. What does it mean to you to have Asperger's syndrome? Can you explain what it means to have Asperger's by using a story about something that has happened to you because of Asperger's?

2. When did you first become aware that you were somehow different from most other people? How did you make sense out of that difference? When did someone first use the words Asperger's syndrome with you? What did that mean to you? Can you tell me some stories about the time when you were first considering the label of Asperger's syndrome?

3. I am especially interested in what it was like for you as an adolescent with Asperger's. Can you tell me some stories about what happened to you as an adolescent that you think were different from the experiences of most adolescents?

4. How have things changed for you since you were an adolescent? What do you think you have learned about yourself and Asperger's since you were an adolescent?

5. What would you like to say to adolescents with Asperger's?

6. When you were an adolescent you were part of an autism program in school. What do you think you learned from that program?

7. One part of the autism program encouraged social interactions for the students in the program. How did that work? Can you tell me some stories about interacting with other people while you were in the autism program? If you were advising the teachers who run the program what would you tell them to do to help adolescents with Asperger's interact with others? What do you still use today that you learned about interacting with others while you were in the autism program?

8. What have you learned about interacting with others since you left the autism program?

How do you think the teachers in the autism program could use what you have learned when they are planning for adolescents with Asperger's?

9. During the interview have you thought of anything else that you want to say or of another story that you would like to tell that explains what it is like to have Asperger's? Is there anything that you would like to ask me?

Interview Protocol for Parent of an Adolescent with Asperger's

The following questions will form the basis of the interview:

1. At what age was your child diagnosed as having Asperger's syndrome? What did you think of that diagnosis when it was first made? You have had some time to adjust to the diagnosis of Asperger's syndrome. What does the diagnosis mean to you now? Can you tell me some stories about your child that would confirm the diagnosis of Asperger's syndrome? Are there some aspects of your child's personality and behaviour that do not seem to indicate Asperger's?

2. From your experience with your child how would you define Asperger's syndrome? Can you tell me some stories that illustrate your definition of Asperger's?

3. Obviously you have many years of experience living with your child. Can you describe the experience of living with an adolescent who has Asperger's syndrome? How has your child changed as he/she has moved into adolescence? How have you changed as you have learned more about your child and more about Asperger's syndrome?

4. If you could stand back and observe yourself as you interact with your child, how would you describe your behaviour? How has your behaviour changed over the years of interacting with your child? Can you tell me some stories that would illustrate how you interact with your child?

5. How do you organize and make meaning out of living with an adolescent who has Asperger's syndrome? What would you like to tell others about your child that would help them to understand him? What would you describe as the joys of living with an adolescent with Asperger's? What are the trials? What has surprised you about your child as he lives with Asperger's?

6. Social interaction is a prime deficit in Asperger's syndrome. Is this true of your child? Can you tell me an anecdote that would illustrate the difficulty that your child has with social interaction? Over the years have you discovered any strategies that help your child with social interaction? What would you advise others to do when they are attempting to interact with your child? What elements are important to include when social interactions are planned for your child? Can you tell me a story about a time when you observed a very positive social interaction for your child? Why do you think this particular social interaction worked well? Can you tell me

about a social interaction that became a disaster for your child? What made this experience such a disaster?

7. As we have been talking have you thought of any other points that you would like to make about Asperger's and your adolescent? Have you thought of another way of explaining what Asperger's means to you? Are there more stories that illustrate life with Asperger's syndrome that you would like to tell?

Interview Protocol for a Teacher of Adolescents with Asperger's Syndrome

The following questions will form the basis of the interview:

1. I would like to know something of your history of working with adolescents with Asperger's syndrome. How long have you been working with adolescents with Asperger's syndrome? When did you first encounter a student who had been diagnosed as having Asperger's syndrome? What was your experience with him or her? What did you think of Asperger's syndrome as a diagnosis at that time? How would you have defined it then? Were there other students that you have worked with that would fit in the Asperger's category but that were not officially diagnosed as having Asperger's? What criteria do you use to fit someone into the Asperger's category? Can you tell me some stories about your first experiences with adolescents with Asperger's?

2. You have now gained some experience with working with adolescents with Asperger's. What are some of the important things that you have learned about adolescents with Asperger's? How do you think you have changed in your approach to adolescents with Asperger's? Can you describe some of your more recent experiences with adolescents with Asperger's?

3. How would you describe life with adolescents with Asperger's to someone who has never experienced it? How do you think you have changed as you have become more and more knowledgeable about the Asperger's community? What do you find yourself doing as you interact with someone with Asperger's? How do you act differently than you first did when you dealt with adolescents with Asperger's? What meaning do you make of Asperger's syndrome now?

4. Research indicates that the ability to interact socially is one of the prime deficits of Asperger's syndrome. Do you agree or disagree with this statement? Can you tell some anecdotes that illustrate your answer? When you are planning social interactions for adolescents with Asperger's what elements do you include? Why? What would you be sure not to do? Why? Can you describe a situation where social interaction was a positive experience for an adolescent with Asperger's? What do you think made this social interaction successful? Can you give me an example of a social interaction that failed completely? Why do you think this interaction was such a disaster?

5. If you were advising parents or other teachers about how to facilitate social interactions

for adolescents with Asperger's syndrome, what would you tell them to do? What do you think was your most successful social experience with an adolescent with Asperger's syndrome? Why did this work? What social experience with an adolescent with Asperger's syndrome surprised you the most? Why? What did you learn from this experience?

6. How do your experiences with social interactions with adolescents with Asperger's syndrome help you to understand Asperger's? How do you make meaning out of Asperger's?

7. Have you thought of any more anecdotes that you would like to tell me about life with adolescents with Asperger's syndrome? What would you like to state about Asperger's to conclude this interview?

Interview Protocol for a Teacher Assistant of Adolescents with Asperger's Syndrome

The following questions will form the basis of the interview:

1. Can you tell me how long you have been working with adolescent students who have Asperger's syndrome? How many of the students you have worked with would fit the category of Asperger's syndrome?

2. I would like you to think back to your first experience of working with an adolescent who had Asperger's syndrome. What did you first notice about him? How did you think Asperger's syndrome made him different from other adolescents? What did you notice about yourself as you started to work with him? At that time, how would you have explained Asperger's syndrome? What did the term Asperger's syndrome mean to you? Can you tell me some stories about your first experiences with this adolescent and with Asperger's syndrome?

3. You have now worked with students with Asperger's syndrome for a number of years. What are some of the things you have learned about adolescents with Asperger's syndrome in that time? How do you think you have changed in that time? What do you see yourself doing as you work with an Asperger's adolescent now? How would you define Asperger's syndrome now? What has surprised you about adolescents with Asperger's? Can you tell me some more recent stories about your work with adolescents with Asperger's?

4. Experts believe that one of the prime deficits in Asperger's syndrome is the ability to interact socially. Do you agree with this statement? What have you observed in your dealings with adolescents with Asperger's that would confirm this statement? Have you observed situations that would disprove this statement? Can you tell me some stories about interactions with adolescents with adolescents that would illustrate what happens in social interactions with adolescents with Asperger's? What do you find yourself doing when you interact with adolescents with Asperger's? What would you advise others to do? If you were planning a social interaction for an adolescent with Asperger's, what elements would you include? What would you be sure not to do? What do you think this means when you think of what it is to have Asperger's?

5. From our discussion have you thought of any other points that you would like to make about working with adolescents with Asperger's syndrome? Do you have some more stories that would illustrate what we have been talking about? Is there anything more that you would like to add?

Interview Protocol for a Speech and Language Pathologist Working with Adolescent Clients with Asperger's Syndrome

The following questions will form the basis of the interview:

1. I would like to know something of your history of working with adolescents with Asperger's. When did you start working with a client who had been diagnosed as having Asperger's syndrome? What did you notice about him or her? What did you notice about yourself as you began to work with this client? How would you have explained Asperger's syndrome at this time? How would you have used your knowledge of speech and language to differentiate this client from your other adolescent clients? Can you tell me some anecdotes that illustrate what it was like for you to work with this client?

2. You have now been working with individuals with Asperger's syndrome for a number of years. How do you think you have changed in that time? What do you observe yourself doing and thinking as you begin to work with an adolescent with Asperger's? What do you think you have learned about Asperger's syndrome? How would you define Asperger's syndrome now? How would you explain Asperger's from a speech and language perspective now? Can you describe an incident that changed your thinking about Asperger's? Can you describe an incident that really confirmed your ideas about Asperger's syndrome? What has surprised you as you have worked with adolescents with Asperger's ?

3. Research has indicated that the ability to interact socially is one of the prime deficits of Asperger's syndrome. Has this been your experience? Do you work with clients who have Asperger's syndrome around planning social interactions? What do you think should be included in such social interaction planning? What should definitely be avoided? Can you describe what you consider to be a positive social interaction experience of one of your clients? What do you think made it successful? Can you describe a social interaction experience of one of your clients that was a disaster? What made it a disaster? What should happen differently next time? What do these anecdotes about social interactions of clients with Asperger's syndrome tell you about Asperger's syndrome?

4. What other conclusions have you reached about Asperger's syndrome in adolescence? What advice would you give to other professionals working with adolescents with Asperger's? What advice would you give to parents and friends of adolescents with Asperger's? Do you have more anecdotes that illustrate what it means to you to approach the worlds of adolescents with Asperger's? What would you like to add to this discussion?