How Can Schools Meet The Needs of Those With Autism Spectrum Disorders (ASD) Including Asperger's Syndrome

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Executive summary

According to Autism New Zealand, 1 person in 100 has an Autism Spectrum Disorder, this includes people who have Aspergers Syndrome. They estimate a population of 40 000 people in New Zealand are on the spectrum.

This paper identifies some of the particular challenges these learners face in the school system due to either their disorder or the nature of typical school activities. It proposes strategies that schools and teachers can utilise when working with these students. Specific areas are identified and strategies to consider in relation to each of these are suggested.

Five key strategies to underpin professional practice are recommended and they are in relation to the giving of instructions, the use of visual or pictorial cues, the need for routine, the importance of a home-school relationship and the effectiveness of teacher modelling.

Many schools and teachers already use the suggested strategies in their classroom practice and find they are effective for a range of learners, not just those on the spectrum.

Purpose

The purpose of undertaking this study was to look at how some schools met the needs of students with Austism Spectrum Disorder including Aspergers Syndrome and to ascertain which approaches and strategies were effective. Professional learning was tailored towards:

- better understanding ASD and Asperger's Syndrome and the impact this has on learners in the primary school
- investigating what other schools have found to be effective to maximise the learning of children on the spectrum
- identifying strategies to support these children in the primary school classroom emotionally, socially, behaviourally and educationally
- identifying factors that are important to consider when transitioning these children from primary to intermediate or secondary schooling

Background and rationale

Autism Spectrum Disorder is a Pervasive Development Disorder which means it affects the individual in every aspect of their life. It is life-long and affects individuals differently so students will have a unique range of abilities and needs. According to Autism New Zealand, 1 person in 100 has an Autism Spectrum Disorder, this includes people who have Aspergers Syndrome. They estimate a population of 40 000 people in New Zealand are on the spectrum. 'Classic' autism affects four times as many boys as girls; Asperger Syndrome affects nine times as many boys as girls. It is found among all races, nationalities and social classes.

In 2008, the Ministry of Education awarded Enhanced Programme Funding (EPF) to Cargill Open Plan School for two years to build staff knowledge of ADD (Attention Deficit Disorder), ADHD (Attention Deficit Hyperactive Disorder), ASD (Autism Spectrum Disorder) and Aspergers Syndrome. This had a significant impact on professional practice and programme development. Since then, the school has continued to work with a consultant who also works with Autism New Zealand.

Undertaking this sabbatical provided opportunities for further professional learning through research, visits, observations and dialogue.

Methodology

The approach taken was to read available literature, engage with experts and to observe the practice of specialists in NZ schools. This proved to be highly effective as the observations were illuminating and the resultant discussions were focused. Being able to immediately discuss what had been observed aided understanding and could be related to the literature.

A specially designated work space at a single-sex secondary school was visited as were satellite classes located at a co-ed secondary school and a primary school. The satellite classes operated through a designated special school and the children had been formally diagnosed and met the criteria for ORRS.

The practice in the secondary school locations varied considerably with one school operating a fully functioning classroom with teacher aides. The other school operated a withdrawal space with no teacher aide support or additional funding available. The children in the withdrawal space were high functioning and, in discussion, indicated that they preferred to complete their work away from the challenges of the classroom.

Findings

There are things that schools should be aware of and contemplate when planning programmes for children with ASD.

Gross and fine motor skills

The inability to perform developmentally and age-appropriate gross-motor tasks has been associated with increased peer rejection and teasing (Attwood, 2007). Difficulties that children on the spectrum display include a lack of coordination and balance, poor muscle tone, physical weakness and poor pencil grip.

- Offering the PMP programme (Perceptual Motor Programme).
- Teaching physical skill development and/or adapting the PE programme.
- Practicing skills on the playground as part of the class PE programme.
- Providing pencil/pen grips.
- Providing pens with flowing ink that are easier to write with.
- Using a computer or scribe.
- Shortening the writing component of a particular activity.

Hypersensitivity and Hyposensitivity

Many students on the spectrum have either hyper or hypo sensitivities and a low tolerance for dealing with frustrating situations and events. Hypersensitivity occurs when one of the senses overloads with too much input due to one or more of the senses being extremely sensitive and becoming overloaded. Hyposensitivity occurs when one of the senses is under reactive to stimuli. Triggers in the student's environment may include sights, sounds, smells, along with touch and taste issues (Silverman et al., 2007)

Strategies to consider

- Exploring the student's environment to see what may be causing the discomfit and considering what can be done to remove the cause of the discomfit or minimise its effect. Consider seating students away from lights, fans, computers, and windows. Children could be provided with head phones or ear plugs to block noise or permitted to listen to their own music to camouflage the noise.
- Considering and minimising potential risks to hyposensitive children who may not get a 'pain' message when they are putting their body at physical risk.
- Identifying potential triggers or situations and preparing the student beforehand eg fire drills, whistles during outside games.
- Discussing the issue with the child and their family as there may be sensitivities that the school may not be aware of that may prompt an extreme reaction, including reactions to inanimate objects eg balloons.
- If triggers can not be eliminated, working with the child to minimise their impact.
- Identifying alternative places for the child to go in order to calm down.
- Identifying which activities provide the child with relief or can be used by the child to self-soothe eg playing with lego, reading.
- Considering different work surfaces and seating options including bean bags and cushions.

Tiredness or lack of sleep

Sleep problems are among a number of secondary behavioural difficulties which may occur in children with autism (Richdale 1999). Sleep disturbances can have a significant impact on daytime functioning including their tolerance, ability to manage their own behaviour and frustration levels, drowsiness and energy.

- Having a rest time during the day.
- Relaxing to calming music.
- Letting children sleep during the school day.

Need for predictability

Many children on the spectrum have a low tolerance for change and unpredictability. Changes in routine and surprises can be difficult. Change, surprise, chaos and uncertainty are not easily tolerated, and the lack of predictability or sameness causes feelings of stress and anxiety. (Attwood., 2007).

Strategies to consider

- Providing a predictable and structured environment.
- Clearly displaying timetables for the week and the day. In some instances it is helpful to break it down even further to a block or session within the day.
- Having individual timetables for each child. Timetables are a key strategy to use. Teachers can use the timetable to avoid engaging in conflict with a child who is reluctant to complete tasks or engage in activities. If the timetable says this is what has to happen, then this is what has to happen.
- Using visual timetables where pictures indicate the activity. Visual reminders tend to be effective as these students are often visual learners.
- Using simplified timetables with the words 'first' and 'then' followed by a picture of an activity. The 'then' is the reward for completing the 'first' activity. When operating effectively introduce 'next' as the second step, between 'first' and 'then'.
- Minimising disruptions once the children are working. If interrupted, some children have difficulty resuming the activity.
- Moving pegs on class lists so children know when to expect their turn.
- Preparing the children for changes to routine by informing them in advance of things like extraordinary school-wide activities and the absence of the usual teacher and the presence of a reliever.
- Training the children to accept change by altering the layout of the classroom and moving furniture around within the classroom.

Friendship

A failure to develop peer relationships is a hallmark characteristic of those with autism (American Psychiatric Association, 2000), and a long-held generalization is that they prefer isolation and avoid social situations (Kanner, 1943).

However, it is now widely accepted that these children want social interaction but may not have the necessary skills or opportunity to facilitate this.

Even though socialization may be arduous, people with ASD do want and do have friends (Bauminger et al., 2008).

- Providing opportunities for children to interact and form friendships with other children.
- Pairing children up with others in the school who share an interest.
- Teaching friendship skills programmes.
- Educating other children in the school about ASD.

Transitioning

Transitions naturally occur frequently for everybody, throughout the day and require individuals to stop an activity, move from one location to another, and begin something new. Transitioning between activities and locations can be difficult and require a lot of energy to confront a new situation. ASD children may have greater difficulty in shifting attention from one task to another or in changes of routine. This may be due to a greater need for predictability (Flannery & Horner, 1994), challenges in understanding what activity will be coming next (Mesibov et al., 2005), or difficulty when a pattern of behavior is disrupted.

Strategies to consider

- Using preparation strategies. Give children a 5 min and a 1 min warning that a transition is coming up.
- Using visual timers or a visual countdown so children can 'see' how much time remains at the current activity before they have to transition to a new one. The consistent use of visual schedules can assist in successful transitions because they allow children to view an upcoming activity, have a better understanding of the sequence of activities that will occur, and increase overall predictability. A number of studies have indicated that visual schedules used in classrooms and home settings can assist in decreasing transition time and challenging behaviours during transitions, as well as increase student independence during transitions (Dettmer et al., 2000).
- Using calming soothing music to signify a transition.
- Using photos, icons, images or words to show the child where they are going next or what their next activity is. Research has indicated that using a visual cue during a transition can decrease challenging behaviour and increase following transition demands (Schmit et al., 2000).
- Providing a 'Finished Box' for children to place things that they have 'finished with' because they are not needed for the next activity. This is another visual strategy that helps in creating a predictable transition routine.
- Allowing enough time for children to pack up at break times so they are not feeling pressured.
- Walking the child to the new location or activity.
- Utilising the support of peers or class members.

Reading non-verbal cues

While statistics vary from 60% to 93%, it is agreed that non-verbal cues are used extensively in all face-to-face communication. Most ASD children struggle to interpret these cues so miss a majority of the communication that is taking place. Subsequently, they can misunderstand the message and respond inappropriately.

- Specific teaching in reading basic facial expressions eg happy, sad, angry
- Teaching protocols for simple social interactions eg greeting each other

Preoccupation with a specialised area or topic (Monotropism theory)

According to Murray et al., (2005) monotropic people have only a few intense interests (depth), and are attention-tunneled; polytropic people have interests that are broader, but not so intense (breadth).

ASD children can become fixated (2005) on particular topics, seeking out information and sharing it in detail with others, who may not share their enthusiasm or interest. At times, this can be a challenge in the classroom or it can be a hook to engage with the child.

Children with Aspergers will retreat into their special interest to escape their anxieties (Attwood, 2007).

Strategies to consider

- Devoting a specific time to focus on their area of interest. Schedule it into the timetable so it has a definite start time and a definite end time.
- Developing a programme around their area of interest as this should successfully engage them in the programme and can be used to teach other skills or concepts. Their area of interest can act as a bridge to other areas.
- Facilitating social interaction around the area of interest by using it as an opportunity to facilitate conversation with others and relationships with peers.

Verbal Communication

There are many rules regarding conversations and the rules change depending on the location, participants and relationships between the participants. The complexity and variability of the rules makes it challenging for children on the spectrum to understand and apply appropriately. It is also makes it difficult for children to grasp and follow multiple instructions.

It can sometimes appear that the child's only interest in communication is to ensure their needs are met.

- Teaching children the basic skills of conversation including looking at the other person, turn taking, responding and not interrupting. These skills are best practiced in conversation so model the behaviours at all times, encourage children to converse and provide immediate feedback or direction.
- Practicing greetings and farewells daily following the same structure.
- Instructing children in appropriate volume for the location or audience.
- Teaching children good manners.
- Giving short, simple, concise instructions, one at a time. ASD children take things literally so be clear.
- Using the child's name before speaking to get their attention.
- Using visual reminders to support your instructions.

Obsessions and Ritualistic behaviours

According to the National Autistic Society UK, although repetitive behaviour varies from person to person, the reasons behind it may be the same. These include: attempting to gain or reduce sensory input; coping with stress and anxiety or blocking out uncertainty.

They can also limit people's involvement in other activities and cause distress both to the individual and to the other people in their environment who are subjected to the repetitive behaviours or obsessions.

- Before taking any action it is important to identify the function of the behaviour. Determine if it is helping them to manage their anxiety, giving them control over their world or helping with a sensory issue and decide if it is really necessary to intervene.
- Increasing the structure in your child's environment and surroundings can help reduce anxiety.
- Having routines. If things are predictable it can lessen the child's reliance on routines of their own making.
- Writing the answer to a frequently asked question (or having a visual representation) and putting it in a readily available location so the child can be referred to that eg on the fridge.
- Pre-planning and gradually introducing the idea of new things when everyone is relaxed and happy. Using pictures of the new things, people, or places.
- Providing a range of activities for children to engage in to alleviate boredom if this is a cause of their ritualistic behaviour.
- Where possible, intervening early as these behaviours are generally harder to change the longer they continue. Further to this, some behaviours will become more socially unacceptable as the child ages.
- Helping the child to identify when they are feeling stressed or anxious and using an alternative response.
- Increasing the child's insight into their behaviour as this can help reduce it.
- Providing an alternative enjoyable activity that has the same function eg putting a child who rocks on a swing.
- Setting limits by rationing objects, imposing time frames or confining to certain locations. Finding alternative activities for the child to do instead.
- Use the child's obsession to motivate or reward them. They can engage in their preferred activity once a less desired activity is completed.
- Make gradual changes as taking away all access to an obsession or trying to change the behaviour instantly could add to the child's distress.

Social skills

Most people have the ability to navigate the social landscape of the world around them. This is referred to as having social skills. For many people with autism, their brains are not wired to enable them to automatically pick up, incorporate and then effectively use the information that is all around them. This information is called the 'hidden curriculum'. It is the social information that is not directly taught but is assumed that everybody knows (Myles et al., 2004). Grandin (1999), who is autistic, claims to have learned by rote how to act in a number of different situations.

Strategies to consider

- Providing instruction for the hidden curriculum. Children benefit from learning these social skills through deliberate acts of teaching. This can include, but not be limited to, greeting people, maintaining eye contact, being excused to go to the toilet, listening to others, personal hygiene and behaviours that are not suitable in public eg nose-picking.
- Including social skills instruction and goals in Individual Education Plans.
- Creating a safe environment for children and actively working to protect them from bullying, teasing or other forms of harassment. Teaching strategies they can use to keep themselves safe.
- Educating the school community about Autism and Aspergers Syndrome so a climate of understanding and support can be cultivated.
- Clearly defining the child's role both to the child and the rest of the group when engaging in cooperative activities. Working to the child's strengths.
- Teaching through the use of Social Stories. These stories present appropriate social behaviours in the form of a story to help students learn to deal with a variety of situations.
- Teaching children to read and respond to non-verbal social cues including gestures, personal space, facial expressions.

Education Outside The Classroom (EOTC)

Taking children out of their usual classroom environment and exposing them to totally new learning and social situations can be particularly stressful for children with ASD.

- Deciding if it is reasonable to expect the child to attend and if you can guarantee their safety and the safety of the others in the group.
- Asking a parent or member of the family to accompany the child on the trip.
- Informing the adults at the venue of the child's particular needs.
- Preparing the child well in advance.
- Ensuring the child is with the teacher or staff member and considering who else, if anyone, could be part of their group.
- Considering what adaptions may need to be made eg travelling by private vehicle instead of on the bus.

Anxiety

The intolerance of children with autistic disorder to changes in their routine or environment is well known, typically presenting with acute symptoms of anxiety, panic, irritability, or agitation (Steingard et al., 1997).

Furthermore, feelings of victimisation and chronic frustration from repeated failure to engage others socially contribute to the development of both depression and anxiety disorders (Bauminger et al., 2003).

- Identifying the child's signs of stress or hyper arousal and intervening early to break the cycle of behaviour, before the problem becomes overwhelming. Signs of stress may include behaviours such as covering or plugging ears, squeezing body parts, or an increase in repetitive behaviours such as rocking or picking at their skin (Silverman et al., 2007)
- Analysing the child's behaviour and devising an Individual Education Plan or a Behaviour Intervention Plan that is personalised to the child and their needs. A Safety Plan may also be required if a child tends to run away or hide when anxious.
- Utilising and teaching techniques that people find calming eg deep breathing exercises, relaxation exercises, listening to music.
- Allowing children to use own techniques or do a favourite activity to selfcalm.
- Identifying a safe area in the school where a child can go to relax. This may include a previous teacher's classroom.
- Teaching children to self-assess their stress level. They can rate their anxiety on a scale or on a colour wheel, traffic light or similar visual scale. This can help identify triggers and enable an intervention to be put in place before the situation escalates.
- Preparing children for possibly stressful, over-stimulating or uncomfortable situations by discussing, practicing, visiting new locations, or meeting new people beforehand.
- Referring the child or the family to other specialists including medical professionals. Medication may be appropriate for some children.
- Balancing structured opportunities for socialising with quiet times to avoid overload and allow time to recover.

Executive functioning and organising

Children with executive functioning deficits often struggle with focus, attention, transitions, organizing, memory, time management, regulating emotions, and managing frustration. These are all skills necessary for children to succeed in school (Giurleo 2008).

The inability to keep track of items and possessions can be problematic.

- Operating a daily notebook between home and school so the adults at both places know what is required and what is happening in the child's world.
- Doubling up on reminders to the child.
- Using visual schedules or rubrics which break tasks down into manageable chunks and describe exactly what is expected of the child. Cut worksheets into sections and present the child with one section at a time.
- Teaching children how to read and complete worksheets they may have not completed it because they didn't know how to start it.
- There are numerous systems and classroom organization strategies that teachers can use but having set places for resources, equipment and books is extremely helpful as is labelling things clearly with meaningful titles eg boxes for Finished Work, Writing Books, Reading Games etc.
- Providing an example of what the end product will look like so children know what they are working towards.
- Sectioning the blackboard or display areas so children know where to look for particular information.
- Using teacher proximity and prompting cues, redirection and feedback to help keep children focused on the task.
- Identifying possible distractions in the environment. This can include noise (clocks), visuals (wall displays) or overstimulation of the senses (flicking lights).
- Teacher modelling.

Auditory processing

Difficulties in auditory processing can mean that ASD may children require a longer processing time before answering. They may reply to your question because they know that is what is required, but there may be no meaning behind the answer. Many of these children repeat the last word you say so if you ask them to choose between yellow and red they will choose red, but if you ask them to choose between red and yellow they will choose yellow.

Strategies to consider

- Using visual aids.
- Using a koosh ball or similar so they 'hold the floor' when it is their time to speak.
- Allowing adequate processing and response time.
- Limiting choices to two.
- Avoiding situations where rapid fire responses are required.
- Practicing on questions they know the answer to eg what are you having for lunch?

School wide activities

There are often times in schools when activities are run with the whole school or groups of classes. This includes assemblies, singing practices, visiting performers, sports days and daily break times. Special consideration needs to be given to ASD children at these times.

- Decide if the activity is appropriate for the child to participate in and in what capacity the child should participate.
- For inside activities, the location of the child can be important. Consider placing the child at the end of a row, near exits or near teachers, away from speakers or heaters. Identify any other factors which may cause the child anxiety and plan around them.
- For outside activities, partnering the child with a peer support person or a familiar older student may be beneficial.
- Making arrangements for the child during break times as these can be particularly challenging.

In addition to the strategies outlined previously Dunlap and Fox (1999) state that to provide effective instruction for students with autism, some general considerations should be addressed:

- 1. Ensure that the student is in good health, free from pain and irritation, and in a safe, stimulating and pleasurable setting.
- 2. Provide structure in the environment, with clear guidelines regarding expectations for appropriate and inappropriate behavior.
- 3. Provide tools, such as written or picture schedules, to ensure that the flow of activities is understandable and predictable.
- 4. Base the curriculum on the student's individual characteristics, not on the label of autism. A diagnosis of autism does not indicate what or how to teach.
- 5. Focus on developing skills that will be of use in the student's current and future life in school, home, and community.
- 6. Carefully plan transitions to new placements and new school experiences. These usually require careful planning and assistance.
- 7. Encourage parents and other family members to participate in the process of assessment, curriculum planning, instruction, and monitoring. They often have the most useful information about the student's history and learning characteristics, so effective instruction should take advantage of this vital resource.

Implications

The implication of these findings is that schools can, with understanding and thoughtful consideration, meet many of the needs of those students on the spectrum. Some schools are already effectively doing so and are making the school experiences for these children less stressful and full of anxiety.

For those schools at the start of their journey, attention will need to be given to the following factors.

1. Teaching skills.

The Ministry of Education, in the booklet entitled Austism Spectrum Disorder ASD: A Resource for Teachers (2008 revised) identifies the particular teaching skills required.

Teachers who find the most success with students with autism spectrum disorder will:

- Have well-structured, predictable programmes.
- Have a quiet and calm manner.
- Be reflective, adaptive and work in a team.
- Be attracted by difference.
- Already be teaching social and cooperative skills.
- Show understanding and compassion.
- Have a sense of humour.
- Not take comments or behaviour personally.
- Be willing to adapt their style of communication.
- Be able to understand levels of social communication.
- Have the imagination to understand and share the mind of someone who lacks imagination.
- Never be satisfied by how much they know.
- Accept that progress sometimes brings challenges.
- Be willing to take on a partnership with parents, families and whanau.
- 2. Professional Development

Teaching professionals and support staff will require targeted Professional Development. This can be accessed from a number of places including the RTLB and GSE services. Vast quantities of information and advice are readily available from the Ministry of Education, Autism New Zealand or online, from reputable sources.

3. Communication

Positive and honest relationships and communication with families is crucial.

Benefits

As for all children, creating a positive school experience that meets an individual's specific learning needs benefits the child, their family and society as a whole. Keeping children engaged and attending school is often vital to their future success. This gives them the opportunity to learn a range of skills and may, in the secondary context, allow them to gain formal qualifications which will enable them to compete in the job market.

Baumeister and Leary (1995) proposed that all people have an innate need to belong to social groups and to form positive interpersonal relationships with others. Carol Goodenow (1993) defined students' sense of belonging as the sense of psychological membership in the school or classroom, that is, the extent to which students feel personally accepted, respected, included, and supported by others in the school environment (p. 80).

Resnick et al. (1997) reported that the sense of school connectedness (or school belonging) was associated with lower levels of emotional distress, lower suicidal ideation, lower levels of involvement in violence, and less frequent use of tobacco, alcohol, and marijuana in adolescents. Other researchers have found perceived school belonging to be associated with lower levels of depression. Adolescents on the spectrum are prone to emotional distress, anxiety and depression so cultivating their feelings of belonging can be of benefit.

Conclusions

There are many strategies that are effective in helping schools to meet the needs of children on the spectrum and, many of them, are strategies that schools and classroom teachers already utilise and are effective in meeting the needs of any number of children.

Five key strategies are:

- 1. Giving clear, concise instructions with no ambiguity so the child knows exactly what is expected and how to be successful.
- 2. Using visual or pictorial cues wherever possible in your teaching.
- 3. Having regular, predictable routines and timetables and display these visually as a reminder.
- 4. Getting to know the child and their family so information can be shared on a daily basis.
- 5. Teacher modelling is highly effective due to its visual nature.

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Helpful websites.

www.altogetherautism.org.nz www.autismnz.org.nz www.autism.org.uk www.autism-society.org www.buzzle.com www.education.com www.iidc.indiana.edu www.jamesmw.com www.minedu.govt.nz/goto/ASD www.moh.govt.nz/autismspectrumdisorder www.nas.org.uk www.selfgrowth.com www.stressfreekids.com

Appendix 1: Six Principles Of Autistic Interaction. By James Williams 23 years-old with high-functioning autism

ABSTRACT : Autistic individuals typically have problems interacting in normal social environments. This leads some parents and professionals to think that they are naturally antisocial. However, autistic individuals, if allowed to interact with other autistic individuals, develop complex friendships that are based on social rules that are unique to autistic relationships. These social rules are not necessarily the social rules of neurotypical individuals. In this essay, I discuss general principles that autistic individuals use when they interact with each other, and how this helps their relationships prosper.

* * * *

[Author's note: The following rules have been read and verified by other autistic individuals.]

There is a basis for the conclusion that autistic individuals are naturally antisocial. Most autistic children do not do well in social situations and prefer to be alone. Some consciously refuse to follow social rules for they fail to see the point of them. Other autistic individuals who do attempt to attain social acceptance may be unable to understand the rules of the majority and hence find themselves despised and rejected.

The underlying cause of autistic social problems is not that autistic people are inherently antisocial. It is that they are social in their own way. But this way is not the normal way, and thus they are perceived to be weird by many neurotypical people.

When two autistic people who are fit for each other interact, there typically are several principles they use when socializing. These may seem alien to you, but remember, many of your values are alien to us even when we learn them.

The word "fit" is key, however. Not all autistic people can find common interests or share worldviews with all other autistics. Some are incompatible. But remember, many neurotypical people have incompatibilities with other neurotypicals.

A few years ago I attended an autistic summer camp. At the camp there was an autistic child who was nonverbal and communicated by screaming day and night. This alienated him from the other autistic children, particularly the boys in his cabin, because they all had sound sensitivities. This caused them to feel impending terror throughout their nervous systems because, without warning, they would hear this child screaming and it would make them fall apart. One child did in fact break down as a result. But this one autistic child who did not have sound sensitivities would not stop because he didn't know why everyone was angry at him. Thus, he was incompatible with the others.

Another important point is that much of this applies only to high-functioning autistic individuals. Many lower-functioning or nonverbal autistic individuals may not have the ability to understand certain social principles, and thus cannot think in terms of

how someone else feels (e.g., "a theory of mind.") Other autistic individuals are very selfish and self-centered with regard to other people, even other autistic individuals. Those individuals aren't necessarily trying to annoy or reject everyone they meet. They just lack a basic awareness of other people.

It should also be remembered that when autistic individuals meet, they have likely dealt with considerable rejection in their lives. They know what it's like to be forced into a social interaction and to fail miserably. So when autistic people meet, an emphasis is often placed on not forcing or rejecting each other, provided that both autistic individuals are capable of understanding concepts of force and rejection that might be separate from their own. They may, in fact, impose no rules on each other whatsoever and may accept any kind of behavior unconditionally. Neurotypical people may again see this as evidence of autistic weirdness when actually it is a form of socializing based on universal respect for others, which is supposedly a neurotypical value as well.

But what are some of the unwritten, nonverbal rules of autistic interaction that most high-functioning autistics would agree upon? I believe they are the following:

1. It is more important to tell the truth than to be polite, unless the person you are talking to specifically states that their feelings are easily hurt.

If one autistic person is bothering the other autistic person, what is the autistic response? It is not politeness or silence. The autistic response is to somehow communicate (verbally or nonverbally), "Look, you're bothering me, don't do that anymore."

If the other autistic person can understand what his friend feels like when he is bothered, then he will stop. His feelings will not have been hurt because of what his friend said; after all, his friend had every right to tell him to stop bothering him. Similarly, an autistic person who does not want to be with another autistic person will not hesitate to say, "I don't want to be with you." In both cases, no one's feelings will be hurt. The truth is better than being polite.

This does not always mean that one autistic child will stop bothering another autistic child. Autistic children who do not have the ability to understand that they are bothering someone do not understand why they have to stop and hence will continue to bother them. I used to bother many people because I couldn't understand why I was bothering them, and didn't see why I had to stop. But the autistic person who is being bothered will not hide their feelings from another autistic person.

Why doesn't the autistic person simply deal with the unwanted behavior of his friend? That is because being polite is not as important as telling the truth. In the normal world, autistic people are often hurt a great deal because someone was too "polite" to tell them they were making a mistake. I have often engaged in what I thought was a successful social interaction with strangers, only to be blasted by my parents afterward about how rude and inappropriate I was. When I complain that no one told me I was being rude and inappropriate, I am invariably told that the other people were "being polite" by not telling me. How is this supposed to help me in the long run? The truth would have been much more helpful. In addition, many autistic people often feel **20** | P a g e

confused when they learn two contradictory lessons in life. After being told earlier that they must always tell the truth, then they are told that they must withhold the truth if it means hurting one's feelings. This is very hard to grasp for an autistic person. To him, you have just lied by telling him two lessons that contradict each other. If one lesson is true, the other must be false. Why did you say that you must always tell the truth if, in certain scenarios, you're not *allowed* to tell the truth? And which is correct? Is telling the truth the right thing to do, or is being polite?

Therefore, in an autistic relationship, only one rule applies: truth wins over politeness. If you don't like someone, you tell him. You say, "I don't like you." An autistic person frequently asks whether he is bothering his friend, even if it is pretty clear he is not. And the autistic person will reply honestly, because he understands his friend's concern. However, autistic people are not bothered by certain things that bother normal people (and vice-versa).

Of course, there are exceptions. I once had a friend whom I thought was very ugly yet since my friend had very low self-esteem, I never mentioned it to him, and did choose politeness over the truth. But I never lied to him about it; I just didn't bring it up.

2. There is no such thing as an interruption or talking too much during a conversation.

In an autistic friendship, a shared interest is often the glue that keeps the friendship together. Two fanatics of *Star Wars* will be friends because they like *Star Wars*. But they aren't really interested in seeing the person, they're interested in talking about *Star Wars*. Therefore, exchanging information is the most important part of the friendship, and who says what and how it is said are of secondary importance.

During autistic conversations, interruption is never impolite. This is for several reasons.

One, the autistic mind, when it hears information, has a tendency to process it in an associative fashion. Often, an autistic person hears a sentence and then thinks about something totally irrelevant to the overall conversation but relevant to the sentence. When the autistic person hears, for example, about how another autistic person loved to eat Polish sausage, the first thing he might think about when his mother went to Poland for a vacation. He might want to talk about how his mother went to Poland, and all of a sudden, the two autistic individuals will be talking about Poland.

However, in order to direct the conversation toward Poland, the autistic individual has to interrupt. Why? Because it only makes sense to mention Poland after the term "Polish sausage" has been mentioned. If he waits until the speaker finishes his thought, then talking about his mother's trip to Poland will be totally irrelevant. Thus, if he interrupts, he gets to be heard by the speaker, but if he doesn't, he won't get a chance to say what he wants.

Two, because autistic individuals have learning disabilities such as poor short-term memory, poor memory storage, and other things, they may have to blurt out their idea as soon as it is formed or they may not be able to remember it when it is their turn to speak. The idea might come and go rapidly, never to return, which makes the autistic 21 | P a g e

person frustrated. Other autistic people have this same problem, and hence, they do not care when someone interrupts them to get their idea expressed.

Three, autistic people often lack the ability to know when another person is done talking. This becomes problematic when autistic people speak with normal individuals. The autistic person doesn't know when the normal person is actually done talking or just taking a breath before starting a new sentence. When the normal person is, in fact, done talking, the autistic person doesn't immediately pick it up and by the time he tries to talk, someone else has already started talking. Thus, in an autistic conversation, there is no such thing as being done. Some autistic individuals even talk until you do interrupt. And when you interrupt, they listen to you, but then just pick up where they left off when you are done.

Many autistic individuals have the habit of talking too much. They will not stop unless you interrupt them. Thus, many autistic people interrupt each other to communicate that they want the other person to stop, as this is the only way they can get a word in. In fact, sometimes autistic people are incapable of stopping—their thoughts just tumble out in a series of run-on sentences, and by stopping them, you are doing them a favor. Sometimes I can't control what comes out of my mouth, and once something gets started, it just keeps going. Our minds are like trains, going from one point to another along a designated track. This is perhaps one reason why autistic children like trains so much.

Because the focus of an autistic friendship is on the information instead of the person, a speaker is usually not offended when he is interrupted. If he is not done, all he has to say is, "I'm not done." If the other person has to speak and cannot hold back, all the first person has to do is wait for a time then interrupt the other person in return. Eventually, all the information is exchanged, and that is the purpose of the friendship.

3. It is always okay to say no to someone else rather than to create a fictitious excuse for why you can't do something with a friend.

If you want the autistic person to play a board game, but the other autistic person doesn't want to, the autistic person will say no. Not all autistic people attain the ability to accept "no" for an answer, but they will likely say no to you when they don't like something you want them to do.

Autistic people, having been forced to do many things themselves, understand what it feels like when another autistic individual doesn't want to do something. When they communicate their wishes not to do something, they are not putting their friend down but telling their friend something they know their friend will understand.

To an autistic person, it's not what you say that hurts, it's whether you mean it. The truth never hurts, but lies and deception do.

When an autistic child is bullied, their feelings are hurt because the bully is deliberately trying to hurt them and figures out clever ways to trick and hurt the autistic person. But when one autistic person says negative things to another autistic person, he is not trying to bully the person but only to convey truthful information.

I once went out to see a movie with a person my age that was on the autism spectrum. She was totally shut down during the movie, and clearly didn't want to be there. Although I understood what she was going through, my mother felt that, in order to be polite, I should call her up and ask to get together again. When I did, the girl told me that she had plans all week and thus could not see me. When it was later revealed that the real reason was because she did not like seeing that movie with me and she was also trying to be polite, I was furious. I felt as if she had betrayed me, and my feelings were hurt. This was not because she had rejected me, but because she had to lie about it. If she could be honest, then I would not have felt hurt. And if I have disobeyed my mother and not called the girl up, then I wouldn't have put her in a situation in which she was forced to lie. So in this case, two normal rules—call someone up out of politeness even if you don't want to, and make up stories about why you can't see the other person—caused both of us to be hurt.

4. Information is neither good nor bad, neither appropriate or inappropriate. It simply exists.

Many autistic people think on what I call a "factual" basis. This is why interruption is non-existent in the autistic relationship even though autistic people frequently interrupt. Similarly, exchanging information for the sake of exchanging information can sometimes offend neurotypical people because autistic people will often point out factual data out when that data is inappropriate or embarrassing.

There's a scene in a movie I once saw in which a man named Edgar, when asked how a couple tragically died in a car crash, replies matter-of-factly, "You know, the fog gets pretty heavy in Scotland. Throw in a curved road, little whiskey—that kind of accident doesn't surprise me at all."

Edgar's statement displays a total lack of sympathy for the people who died. However, it is unlikely that Edgar feels this way. Although it is not mentioned that Edgar is autistic, this is something that an autistic person might say and not find anything wrong with it. Why? Because autistic people generally think in terms of stating factual information free from emotion.

One day, when I called up one of my autistic friends, she announced to me that she was getting her period. We both knew that typically a girl wouldn't always share that information to a guy, but we also know that since we were both autistic, she just felt she had been sharing information to me about herself. I understood it the same way. To us, that was just a sharing of information, and we didn't feel bothered by it, regardless of its sensitive nature. Some (though not all) autistic people I know, in fact, aren't bothered by sharing personal information about their bodies or from their past. I even jokingly replied, "If I were more seriously autistic, I might have looked at a calendar and told you what day of the week your next period might start one month from now."

Oftentimes this is not an issue when autistic people are talking to each other because what they talk about is independent from feelings such as embarrassment. Two autistic kids who talk about trains and the details of different train routes, such as taking the Red Line subway route or the Blue Line subway route, do not typically talk about how they feel about trains or how the trains are feeling. And what's more **23** | P a g e

important is not the people themselves, but the fact that they both are fascinated with trains.

5. Relationships are often oriented around mutual mental interests and not physical appearance or attraction, or gender.

I was once told that the symbol of the nerd is the plastic penholder and ballpoint pens inside the front shirt pocket. I think another symbol of the nerd is the focus on mental interests and the indifference toward physical appearance, whether his or another person's.

This is also an attribute of an autistic relationship. Often autistic people are not focused on the appearance of the other person but on what the person is interested in. As mentioned above, *Star Wars* fanatics talk about *Star Wars* and focus on facts about the movies, not how anyone is dressed or how their hair is cut.

This also sometimes produces a cavalier attitude toward one's own personal appearance. Many autistic people can't be bothered with what they look like. There's a lot more better stuff to think about. And often times they have no sense of ugliness—to them, people are neither ugly nor beautiful. They might wonder why people who are fat, for example, are teased and made fun of by others.

This issue also occurs when autistic individuals create friendships that they perceive differently than the way other people perceive their friendship. For example, society-and by "society" I mean other people, even children--looks at friendships between a boy and a girl, or a man or a woman, differently than friendships between two boys and two girls, or two men and two women. My mother pointed out, for example, that when I saw that movie with the autistic girl, I had to pay for both tickets. (Ironically, the girl with autism was oblivious to this.) But, as she pointed out, if I had seen a movie with another boy, we would be allowed to pay for our own tickets.

When an autistic person meets someone with similar interests, it often doesn't matter whether the friend is a boy or a girl, short or tall, younger or older, or even in the same room or the same country. What matters is that that person is their friend—someone they enjoy talking to and hanging out with. And isn't that what the true definition of friendship is all about?

These days, with the Internet, autistic people are able to find deep and satisfying friendships with people that they have never met and with whom they communicate only in chat rooms and by e-mail, or just by phone. Sometimes, these friendships are ideal for many people with autism, since they focus only on information, not the person's physical presence.

6. There are exceptions to all social rules; in fact, even the social rules mentioned above aren't always followed.

As the singer sings in the song *Everyday People*, "Different strokes for different folks."

While I was talking about autism in a general sense during this essay, autism is a very diverse disorder. Just as normal rules are infinitely complex, so are autistic rules. It works both ways. This essay is not meant to be a guide for normal individuals to help them interact with autistic individuals; none of the advice shown here will help you do that. It will help you understand *some* autistic individuals, especially myself, as this is how I have experienced social interactions, but every autistic person is different.

For example, some autistic individuals are married and capable of committed relationships with a husband or wife. Stephen Shore, an autistic speaker, is married. So is Liane-Holliday Willey, the author of an autobiography about autism. And many autistic people are polite to each other even if it means withholding the truth if they feel that they must be polite to not hurt the other person's feelings.

Therefore, the solution to the problem of not having friends is to also realize that "not having friends" isn't necessarily a problem unless a person needs other people in order to get by. If this is the case, parents and professionals should give autistic individuals opportunities to interact with other autistic individuals, and to acknowledge that autistic individuals have their own social rules that may be odd or embarrassing to you but are not embarrassing to them.

And once there is mutual understanding, we all-—the normal and the autistic individuals of the world—will attain a much better theory of mind toward one another.