

APENDIX 1

SELECTED INTERVIEW

Biographical Details

Researcher: Current Age.

Parent: 14 Years 5 Months.

Researcher: Male or Female

Parent: Male.

Researcher: What kind of school is M currently?

Parent: M has just begun schooling at a regular Afrikaans government school.

Researcher: What grade is your son currently in?

Parent: Eight.

Researcher: Has M ever repeated a grade?

Parent: One.

Researcher: Do you feel that repeating grade one was beneficial for M or did it cause more socialisation problems?

Parent: M is overly conscious that he repeated grade one and that he is a year older for his class. These kids are normally over sensitive, and I don't think keeping them behind benefits them socially but I keep on explaining to him that I don't care if finishes school when he is 24, the main goal is to finish

Researcher: What type of work do you actually do, and could you tell me a little about your personal educational qualifications?

Parent: I am Personal Assistant to the Divisional Director of a Technology Management company. It's a great company to work for and I wouldn't even change for more money.

I have a standard 10 and actually passed with 3 A's, but I had two brothers who went to university and there was no money for the girls to learn, although I'm also lazy. I was never interested in learning after I started work. I do a lot of short courses and computer courses at work which keeps me informed, but I leave the big stuff to the clever people!

Researcher: Does M fend for himself every afternoon while you work? It really must be so difficult for you working a full day and having to worry about a son and running a home

Parent: I'm extremely proud of M. I say his achievements are truly his on his own, I don't take any credit. He is so responsible and has been looking after himself since I can remember. The principal gives him a lift till his home and then M takes the bus home but mostly he walks home (he says he needs the exercise). He is never in the street, I can phone

him everyday at exactly 14h30 and he will be there, he never leaves the flat not even to the cafe without phoning me and telling me. I just forced this concept into him because I work full day. I always explained to him that I do not want to worry about him and that I always have to know where he is. Last year he had some friends who drank and smoked (at the age of 12 to 13!) can you believe it! Yet I never ever worried that he would do it. I just kept on explaining the pros and cons to him endlessly and he tends to understand. I'm really very proud of him, he left those friends on his own, after I explained to him when children are using you and when it's a give and take situation etc. I don't know if it will always be that easy, because he is becoming older and is a bit more moody and snappy lately!

Researcher: At what age was M diagnosed with Asperger's Syndrome?

Parent: He was only diagnosed with Asperger's Syndrome in September 2000!

Researcher: Who diagnosed your M with Asperger's Syndrome?

Parent: A doctor who is a Child Specialist in Developmental Paediatrics.

Researcher: When did you first have a feeling that M may be different and why?

Parent: As a baby I already had a feeling something was wrong because he never slept, never smiled or laughed spontaneously, didn't recognise me as his mom till much later on, never seemed pleased or excited to see me, and acted the same with every person.

Researcher: Was M ever misdiagnosed – for example with ADD?

Parent: All the time, since the age of two years, especially with ADD and also Bipolar Disorder (depression). The frightening point is that he was taking medication (schedule 7 drugs!) for all these incorrectly diagnosed disorders, e.g. Ritalin and anti-depressants!

Researcher: Were there any complications during your pregnancy or birth of M?

Parent: M was a bridge baby, I had a caesarean and was under anaesthetics, and therefore, I cannot tell if the delivery was normal or if there were any complications at birth.

Researcher: Did M suffer from any major childhood diseases?

Parent: No

Researcher: Is there anyone else in your family that has been diagnosed with Asperger's Syndrome?

Parent: No.

Social and Emotional Impairments

Researcher: Do you agree that the social / emotional impairments are the most significant?
Please elaborate by giving reasons for your views

Parent: Yes the social / emotional impairments are definitely the most significant. M doesn't like to take turns - when playing cricket for example, he wants to change the rules to suit him. He does not stop talking about his topic even when you are not listening. He does not understand sarcasm, when you are really angry he thinks it is really funny. He does not know when to stop unless I send him to his room. Most of the times he does not care or feel hurt when you reprimand or say nasty things to him. He does not read body language at all. To give you an example his previous school unloved him, the teachers nor the children wanted him in that school, they made our life misery, and yet when there was a Box Car Derby on a Saturday at that school, he went there for the day. I asked him if he wasn't upset or scared going there and he said no, meaning that he does not care or understand how others feel or think about him.

Difficulties playing with other learners

Researcher: Does M lack an understanding of how to play with other children? For example, unaware of the unwritten rules of social play.

Parent: He has learned to play with other children, to the extent that if they skateboard, he wants a skateboard, if they ride bikes, he wants a bike. He has become very accommodating because he learned that this is how he will have friends, but he still doesn't understand why or when they are mean to him or when he is irritating them.

Researcher: Do you have any other children? How do they get along?

Parent: No! M gets along well with older or younger cousins. Also maybe being an only child and a single parent has made a difference.

Researcher: Can you elaborate on M's dealing with his friends?

Parents: M is very easily influenced by friends because of his syndrome. I have to intervene all the time or else he will do silly and dangerous things. It is difficult for him to find and make friends, so he will almost sell his soul to have friends. For example two years ago he gave away his shoes, skateboard and clothes to friends (buy their friendship). It took me two years to explain that it is a give and take situation (try and explain this concept to an Asperger) as they take things literally. I had to explain that you don't give and take material things, it's a friendship, emotional give and take. I think he still does not understand this concept, because if a friend comes to his house and he gives his friend cookies and cool

drink then when he goes to the friend's house he will ask the friend "you have to give me cookies and cool drink. Luckily he has stopped doing that.

Last year, I was also afraid because he had some friends who smoked, at the age of 13, and I was scared that they would influence him. Knowing how serious it is I told him that he could smoke but that he would surely die because he has Asthma (he hasn't got Asthma). I try not to interfere with his friends but I keep a close watch, as I don't want them using him. He has no idea what friends are supposed to be. He wants to be friends with this one boy but the boy said he must have such-and-such a skateboard first and that is when he will put pressure on me to buy this particular type of skateboard because his friends say he must have **THIS** type of skateboard (**NOTHING** else, it must be **THIS** type of skateboard).

I must admit though because of all my intervening and protecting he has left all the smoking friends and friends taking his things, because the last time his friend took his skateboard and never brought it back, I refused till this day to buy a new one. I have made M suffer and now at last he is angry with the friend. This is the only way I could make him feel for me which was to make him feel! It is also the only way to make him see that friends can harm you. He has much better judgment now, and because he likes routine, he is very responsible and always lets me know where he is and where he is going. I also have a very open relationship with him and encourage him all the time to talk to me about everything: sex, girls, smoking, stealing whatever I can think of that can be bad for him, that way at least I hope that he will be okay to tell me everything. When he tells me what his friends do, I don't judge them too hard because I know then that if he does the same thing he knows I will judge him and that would be a reason for not telling me what he is doing (and what his friends are doing). When, for example, he told me that one of the boys in school stole a cell phone from the teacher I asked him what he thought about it and I listened to his judgment.

Researcher: Do you think that M plays better with other learners with Asperger's Syndrome or does he prefer to socialise with his regular peers?

Parent: I don't know if the other parents find it the same but I think M copes MUCH better with "normal" kids than with other children with Asperger's Syndrome. M has no friends with Asperger's Syndrome. I once introduced him to a friend with Asperger's Syndrome and they did not get along at all, because they have no feelings. It seems as the regular kids have more feelings and understanding and patience with him.

Unaware of peer pressure

Researcher: Is M indifferent to peer pressure? For example, does he follow the latest craze in toys or clothes?

Parent: No, to the contrary he watches what other children wear and then wants to wear the same or look the same and will wear nothing else. If a child should make a remark about his jeans, for example say they are fake, just one remark and he will refuse to wear them at all even if I threaten him!

Unaware of social conventions

Researcher: Does M appear unaware of social conventions or codes of conduct and make inappropriate actions and comments? For example, making a personal comment to someone but he seems unaware how the comment could offend.

Parent: Absolutely, just for example to make sure that he brushes his teeth properly I would tell him that his teeth still look a bit yellow. So when we visited a friend one day he asked, "did you brush your teeth?" When the friend replied "yes", M said, "are you sure they still look a bit yellow." How embarrassing!

Incorrect distance between listener

Researcher: When communicating with M will he perhaps stand too close or too far to another person?

Parent: M has the habit of standing far too close too everyone. He stands right next to you and also walks almost on top of you. He is extremely clumsy, drops things, bumps things, bumps into you etc.

Incorrect eye contact

Researcher: When in a conversation, does M use less eye contact than you would expect?

Parent: Yes.

Body language / Face perception misunderstood

Researcher: Will M understand the meaning of a smile or frown – for example if you show a cross face will he understand that there is something wrong - in other words the meaning of body language?

Parent: He does not understand body language at all. I can be so irritated and serious and have any face I want, he will think it's funny and keep on laughing. He thinks your face looks funny when you are angry and instead of concentrating on the angry face he is concentrating on how funny it looks. He laughs endlessly at anything on TV and mostly because of the peoples' expressions more than anything else. I have to make physical

contact with him by sitting right next to him, tell him to look in my face, make him concentrate and then tell him that I am now really upset. It is best if I first send him to his room to stop laughing - sending him to his room just for a few minutes makes him understand that the talk coming up is serious, this seems to be a signal for him that this is not a joke anymore. But facial expressions mean nothing to him.

Misunderstands the hidden curriculum

Researcher: Will M understand people pleasing behaviours? Does he understand what each individual teacher expects even though not specifically outlined each lesson, or even which learners to avoid because of their unruly behaviour?

Parent: No he has no hidden agendas, it doesn't even help if the teacher is nice, a teacher can be very kind and then tell him the next day he did something wrong and then he will say he doesn't like her. He will do exactly the same thing in the strict and the kind teacher's class.

M knows no difference between bad and good friend, bullies or no bullies, being used or not used. Some kids are so horrible to him, but he stays their friend and does not stay away from them.

Emotional Impairments

Emotional instability / depression

Researcher: Emotionally, is M a happy child or is he often sad - can you describe his emotional stability?

Parent: M is emotionally stable, but he is overly serious and anxious, he tends to believe everything he hears. If his friends tell him he is going to fail this year, he will be worried about it until I convince him that they are wrong.

He does have a little bit of depression. His moods always depend on what day he has had, so I reckon we cannot call it depression as we feel the same. I usually make him snap out of it very quickly by explaining things and showing him the lighter side of what he is thinking. I would rather call it more anxiety than depression. The other day he was really feeling down because I moaned at him. I wanted him to get off the skateboard thing for a bit – he has developed a skateboard attitude as well. He told me that he is a skateboarder because he is a loser or something like that, e.g. skateboarders have a loser's attitude and this resulted in a fight. I explained to him that the reason why he felt so down is because we had a fight and that made him feel insecure. I explained to him that I have loved him for 15 years, and even

if we fight I'm going to love him more for another 15 years. It made him smile, so you can see that whatever impacts on him that day, makes him feel depressed the next day.

He will get depressed and angry and will carry on until he gets what he wants (for example a new skateboard or bike). I know all teenagers are like that but it's more difficult for him to understand "no", especially when he is totally fixated on something.

They were asked at church to write on a mask how they feel about themselves and he wrote: A sense of worthlessness; always feeling insecure and uncomfortable; low confidence and self-esteem. I really find it so disturbing as I spend so much time telling him how wonderful he is, how handsome he is and how clever he is and then when we have a fall out he gets all his negative feelings back. Maybe I'm also pushing him too hard and overdoing it, but his answers were quite upsetting.

Realises his differences

Researcher: Does M realise that he is different from the other children? Can you elaborate?

Parent: Yes he realises it, but he thinks other children are different from him (he's not different - they are). He often comes home and says he's a freak. When I ask him why he says that he just says he knows he is, children look at him as if he is a freak.

Temper tantrums

Researcher: Does M have many temper tantrums? How you deal with them?

Parent: When he was small his tantrums were uncontrollable. He did not sleep at all. I could not go anywhere or take him to anyone. Now that he's older and since he has been diagnosed it's changed dramatically, because now I understand and know how to handle him.

Researcher: How did you manage to handle the situation when a temper tantrum arose?

Parent: I could never manage the tantrums, they never stopped. I almost went off my head and almost killed him. I took him from doctor to doctor. I had no idea what was wrong with him. I did not know why he never slept and why he threw these tantrums. Luckily a doctor thought he was hyperactive. He just told me to accept it, and that I should change and learn how to live with it. From here on I changed and accepted that my child was Hyper and could not help it.

Cognitive Impairments

Visually orientated

Researcher: Do you think that M is more visually oriented, for example he will understand something easier if you explain it to him in pictures: Have you heard of comic strip conversations

Parent: Visual aids could help but I have never used these. I do explain everything by using a lot of hand and facial expressions, not pictures, more role-playing. Maybe pictures would have helped when he was younger but I have to admit I have never tried the pictures. Like I said, maybe when he was younger, but what pictures do you show a teenager to explain things that they want to know – they need answers to all of life's questions now, and not see comic illustrations?

I have never heard or seen comic strips or social stories that can help these kids but one thing I can ASSURE you is that teachers are not interested at all, they have enough to cope with. With 40 children in a class, never mind children with learning disabilities, they are not equipped nor interested either. These children really have NO WHERE to go.

Flexibility in thinking

One track mind / double barrelled instructions

Researcher: Would you say that M has a 'one track' mind – only being able to concentrate on one thing at a time? In other words if he is given a double-barrelled instruction to follow, will he accomplish all the tasks required?

Parent: M cannot do double-barrelled instructions, or remember two instructions. He struggles to organise himself and battles with time management. He will spend too much time on certain homework and no time on other important homework. He will forget if you ask him to buy bread and milk at the shop. I tell him to remember that he has to buy two things, and when he gets to the shop he must remember what the two things are, he must only remember the amount two - even then he will not come back with both milk and butter.

Unable to learn from previous mistakes

Researcher: Will M be able to learn from previous mistakes – in other words not repeat the same errors?

Parent: It takes years to learn from previous mistakes. Once there is a mind blindness – for example you are not allowed to ask questions in class, he will do this for years in every class even if he gets into trouble or is placed in a different school that encourages questioning.

Inability to accept failure

Researcher: Will M get very angry if you tell him he is wrong – in other words does he find it difficult to be wrong and is adamant that his views are always correct?

Parent: M is never wrong, but if you explain very kindly and very patiently to him why he is wrong he will admit and confess. If you suddenly confront him, or you shout he will definitely tell you that you are wrong and he did nothing. If he talks in class and the teacher punishes him, she is wrong, she should apologise, because she did something bad to him. If you punish him it only means one thing **YOU DON'T LIKE HIM** end of story, and then he does not like you either!

Theory of mind

Difficulties with social imaginative play

Researcher: Does M lack social imaginative play? For example, other learners are not included in his imaginary games or he is confused by the pretend games of other learners.

Parent: M has never engaged in imaginary games, and he still does not. Even as a child he did not understand this concept. He does not participate in any sports as he does not understand the rules, e.g. cricket, as well as card games, have too many rules for him to understand. Other kids get too impatient with him when he does not stick to the rules of the games. He enjoys things he can do on his own like skateboarding and riding his bicycle.

Enjoys only non-fiction books

Researcher: Does M read books primarily for information, not seeming to be interested in fictional works? For example, being an avid reader of encyclopaedias and science books but not keen on adventure stories.

Parent: He loves drawing, hates reading but in the private school last year, he had to read a lot because it's a self-learning school. I asked him what books he would like to read if he had the time to read, and I think because he is a teenager he said that he enjoys reading helpful books, like the book I gave him to read called "what every boy should know". He wants to read books that can help him understand himself and motivational and social books, that is what he calls helpful books. He would probably enjoy true-life stories where people have made a success of their lives, I think you call it biographies. He also enjoys scary books. He loves his skateboard magazines and sticks skateboarders all over his room.

Truly the kids have no time to read. They have homework in all their subjects daily and the schools are task driven, so in high school you probably end up doing a task every week. I cannot see how you can still expect the child to read for leisure, if they do sport and get

home at maybe 4 pm and then start homework. In the week we never even switch on the television, and on weekends I encourage M to get out of the house - not to read, but to rest.

Inability to explain his emotions

Researcher: Can M explain his own emotions – how he is feeling?

Parent: M often gets depressed and then says that he does not understand why he is feeling so sad. I tell him that it's his hormones and that it is natural. He asked me last night if I want to see his diary, I asked why and he said so that I can see that he did not write anything nasty about anyone. I told him that it is his diary and he can write what he wants even nasty things and that it is not necessary for me or anyone to see it. I told him that the only secret he is not allowed to keep is if it is dangerous to him, like if he smokes or drinks.

Lack of empathy

Researcher: Does M lack empathy, i.e. the intuitive understanding of another person's feelings? For example, not realising an apology would help the other person feel better.

Parent: Most of the time. Last year when I was in tears about his previous school, he merely said "OK mom, I'm going to the neighbours", not why are you upset or so forth. He cannot anticipate anger either. I can warn him about the same thing that annoys me over and over and over again, for example do not take your shoes off in the lounge, but I first have to totally lose my temper before he knows that I'm serious (maybe it's also a teenage thing).

To give you an example of no compassion, a lady came to his old school and confessed to being on drugs and how she has changed her life etc. What was considered as heart rendering for all the kids, M only wanted to know one thing "if she was high and how did it feel to be high" - totally inappropriate! He wasn't being sarcastic, he really just wanted to know how this felt, scary!

A girl living close to my parents spread the word that she liked M, but M did not understand the hints. He got angry when someone mentioned that she liked him so he called her a lesbian! I do not know how he heard that word or even knew what it meant but he did not understand the remarks people were making, that she liked him, were meant in a nice way.

Another example, he has been going home by bus for years and one day I decided to surprise him and pick him up at the bus stop, it was really hot. If it was my mom who came to pick me up I would have given at least a little smile and looked a bit surprised. When he saw me at the bus stop there was absolutely no expression on his face at all. He merely got into the car and did not even ask why I decided to pick him up. If I did not understand his syndrome

I would have thought he was extremely rude. This is what most people think about these kids because they do not understand their lack of feeling and expression.

Regarding empathy, the other day I had just bought him R500 Reebok takkies and all he did was complain non-stop because he said they were too big. He wanted a size 8 and I bought him a 9. Now he refuses to wear them and does not stop complaining. It seems as if he is so ungrateful but in the meantime he does not care how I feel because he does not know how I feel. While I was crying he just carried on talking and laughing about other things.

Regarding apologies, in his old primary school the principal was very adamant that he would keep on punishing M until he apologised. He stood in front of the staff-room every day, every break, he stayed for detention everyday after school, the principal even mentioned M's name in the school hall twice. I gave M a terrible hiding and still he did not apologise.

M has now learned to apologise but still has no idea why he has to do this - he does it because he learned it's what he must do. He apologises so much now that it irritates me. If I say M why are your shoes in the lounge "sorry mommy", hurry up we are late "sorry mommy" and it carries on and on and on. I said to him the other day "please don't be so apologetic!" He has NO idea what apologetic means. I explained to him that he should say sorry only if he REALLY means it and that he should do his utmost not to repeat what he has apologised for. He has no idea what this means.

Expects others to know their thoughts

Researcher: Does M seem to expect other people to know their thoughts, experiences and opinions? For example, not realising you could not know about something because you were not with him at the time.

Parent: He offers no information at all. I have to drag information out of him. Just as an example, M went to Kung Fu one evening and I asked him, where, when and how much - he became so irritated because I should have known all of this.

Ability to deceive

Researcher: Can M tell a lie or will he always insist on telling the truth, even becoming a tattletale?

Parent: He can tell a lie. Yesterday I asked him why he sits and plays in the class. He denied this, but after talking to him he confirmed that he was playing with his pen. The reason why he lied is because he immediately thought the teacher is wrong and does not like

him. I then told him that she does like him and explained that he was wrong to be playing in class. Only then did he admit that he was wrong.

Difficulties with pretend play

Researcher: Can M hold two conflicting ideas simultaneously? For example, if an object is to be used as a 'pretend' for something else - say, a cardboard tube for a telephone.

Parent: M does not like "pretend." If he is given a cardboard and asked to pretend it is a telephone he will be angry or die laughing. He will think it is stupid.

Language Impairments

Researcher: At what age did M start speaking?

Parent: Very late, after about two years. That's when I started taking him to speech therapy. They thought he did not speak because he was confused with two languages - I spoke Afrikaans to him but he was in an English Crèche.

Researcher: How would you describe M's language abilities?

Parent: He speaks fluently but does not understand when spoken to. He does not understand idioms or the implied meanings of advertisements on television.

Pragmatics or the art of conversation

Difficulties repairing a conversation

Researcher: Does M have problems repairing a conversation? For example, when he is confused, he does not ask for clarification but simply switches to a familiar topic, or takes ages to think of a reply.

Parent: It's yes or no or takes ages to think of a reply. He lip reads when people talk. If he knows or feels comfortable with the person he will ask, "wait-wait what did you say?"

Verbal fluency

One sided conversations

Researcher: When talking to M does he appear uninterested in your side of the conversation? For example, does he ask about or comment on your thoughts or opinions on the topic?

Parent: No, unless he is asking the questions.

Researcher: Could you please elaborate on this point? Does this mean he is interested in what you are saying?

Parent: M does not listen with interest if you talk about anything except if it's something he specifically wants to know, like, for example, why did that man say that, then he will listen. He enjoys it when he is given a lot of explanation. He only makes conversation when he can spew out his interests, and does that whether you are listening or not. When you want information from him though, for example, what did you do, where did you go etc. you have to literally drag it out of him.

Literal interpretation of comments

Researcher: Does M take a literal interpretation of comments? For example is confused by phrases such as 'pull your socks up', 'looks can kill' or 'hop on the scales'?

Parent: Something as simple as "don't dig up the past" is something I had to explain to him just last week. He has come up with some interesting little things in the new school though. He said the Afrikaans children are extremely "windgat", I assured him that they probably think the same of the English kids. He also called the teacher "oom" and the teacher told him "ek is nie met jou tannie getroud nie" so I had to explain to him what it means. He really battles to have friends, and when he does make a friend these usually do not last long because he does something stupid. His last friend had television games that he really enjoyed playing and M used to just phone his friend and say "can I come to your house to play games?" I explained to him that his friend is going to think that he is only using him for his games, so the next time M phoned his friend he said "can I come to your house, I don't only want to play games."

He does not understand jokes at all. I have to explain the jokes to him and even the simple adverts with implied meanings - I don't know if you saw the new one where the guy chases with his Opel and they mistake him for Bond, he does not even understand that.

Prosody or the melody of speech

Unusual tone of voice (monotone)

Researcher: Does M have an unusual tone of voice? For example, does he seem to have a 'foreign' accent or monotone that lacks emphasis on key words?

Parent: To my extreme frustration he copies people's facial expressions (not their voices). He often has different facial expressions, which he imitates from someone else. Every week I have to ask him "who are you now M?" The once I saw him sitting with his mouth open and a dropped jaw, and he said that he was one of his friends.

Researcher: You say that M copies his friends' facial expressions - what about their voices, is this included and what about M's regular voice, is this monotonous or not?

Parent: His voice is perfect and not monotonous anymore. He likes to copy people's talking on adverts but does not do this often. I suppose most kids do this. His language is normal and his voice is normal. It is only if he sees someone with a peculiar habit like leaving their mouth open then he will copy and leave his mouth open.

Pedantic speech

Researcher: Is M's speech over-precise or pedantic? For example, does he talk in a formal way or like a walking dictionary?

Parent: No, but he had a lot of speech therapy. I think the speech therapy helped him when he was very young. He went from the age of 2 for a year and then at the age of 8 again for about 2 years. It probably helped to give him a bit of confidence to speak, but I do not think they realised that understanding and socialising was the actual problem. I would not send him today as he has no problem with speaking only understanding. Any therapy is never a waste but I never found the therapy that he really needed, except for desperate understanding and support from teachers and the school.

Idiosyncratic use of words

Researcher: Have you ever noticed if M has the ability to invent unique words (neologisms), or is idiosyncratic or original in his use of language?

Parent: When M was younger he used to say unique words that were far beyond his age but now he uses age appropriate language.

Exceptional long term memory

Researcher: Does M have an exceptional long-term memory for events and facts? For example, remembering the neighbour's car registration of several years ago, or clearly recalling scenes that happened many years ago.

Parent: He had an exceptional memory when he was younger but now he has the usual teenage things on his brains - girls and friends.

Narrow Interests

Researcher: Is M fascinated by a particular topic and avidly collects information or statistics on that interest? For example, does he become a walking encyclopaedia of knowledge on vehicles, maps or league tables?

Parent: I never allowed him to be obsessive with one thing. However, if he is busy with something you will not be able to motivate him to do something else until he is finished or has had enough of what he is currently doing.

Researcher: Can you also name some of the topics he is interested in? Do these change from time to time or has it been one particular topic all the time?

Parent: He has various interests, I suppose I never gave him the satisfaction of getting obsessed with one thing. He has Asperger mildly so is not like another Asperger child who is an expert in Dinosaurs or trains etc. He likes BMX, and can name all the tricks and styles, then he will like skateboarding and once again can name every single trick, style, clothes skateboarder's names, then he will listen to Rap music and will tell you every song or singers details. He seems to get a lot of information from I really don't know where and remembers the facts when it's something he is interested in. But as I say, he has two or three interests and then will not partake in sports at school or be persuaded into doing anything else. I am actually dragging him to Kung Fu at the moment, he has already lost interest. He always reverts back to his bike and skateboard. He loves talking about his bikes and skateboards and can talk on these topics, non-stop, for hours.

Researcher: How do you deal with M's obsessions? Do you ever try and limit his playing or use it as a reward when he has done something good - though you did say that they are not a major issue?

Parent: M is mostly past obsessions. He just gets weird moods and does strange things, mostly bad habits. He used to click his knuckles endlessly for a year, and then walked around with his mouth open all the time. The other things I cannot quite remember. He now has this ugly habit of playing with spit in his mouth, and non stop! I shout at him every time he has a habit and tell him how ugly it is. I give him some time to try and get over the habits, give him lots of warnings that if he does not stop I will smack him. If he does not then I do eventually give him a hiding, but I first try to make him aware of every time he does it. I show him how ugly it is and then tell him that I'm going to do it when we are in town together so he can get embarrassed. At least he is at the age now where his mother embarrasses him in anyway!

Repetitive Routines

Researcher: Does M develop elaborate routines or rituals that must be completed? For example, lining up toys before going to bed.

Parent: Yes he still sticks his soldiers to the floor with prestik in his room and then tells me I'm not allowed to clean his room for days. I allow this for some time and then I ask him or encourage him by asking him if he does not think he should pack it away.

He even has a pattern for his friends - he will first phone Mike, then Chris far away and then Chris opposite the road if he wants to go and play. He will stay Mike's friend for life even if Mike never wants to see him. He will always phone his friends in this order.

Researcher: Does M become unduly upset by changes in routine or expectation? For example, is he distressed by going to school by a different route?

Parent: When he was younger very, but now he is okay. I still give him enough warning where we are going but at school all the class changes and teachers changing are very frustrating to him. He feels comfortable with routine, loves reassurance - especially now that he is a teenager he wants to know all the time, "am I strong", "am I good looking", "am I clever" etc. He loves lots of explanations, for example, what happened and what did this man say on television and what did he mean when he said that etc.

Movement Impairments

Researcher: Does M have poor motor coordination? For example, unskilled at catching a ball.

Parent: He is very clumsy and accident-prone. He cut his leg open last week by falling on a rock and then three days after that he cut his fingers on a broken window. I always have to tell him to watch out.

Researcher: Is M interested in participating in competitive sports, games and activities?

Parent: He is an excellent swimmer and has come first in galas but when I asked him why he does not swim, he says because he knows he can swim! He dislikes competitive or group sports. He likes participating more in just skateboarding, BMX riding or Kung Fu.

His new high school is very proud of their sports, they insist that all children participate. To them it is just as important to be in the F team as to be in the A team. They have so much sport to choose from - table tennis, tennis, cricket, rugby, then other activities like debates, revues etc. They insist that each and every child should participate in at least one thing. M tried the athletics but like his mom he is very slow and not an athlete - he said the nice thing

was that the teachers kept saying “try again” and “try again.” When he did not join the athletics he at least enjoyed learning and singing the new sports songs.

He surprised me because this morning he took his cricket bat to school and said he is staying after school to try cricket. He also said that if he does something like cricket the teachers and children will respect him. He is realising that this is a way to get accepted and liked (I’m positive that he is starting to learn some social skills at last!).

Locomotion

Researcher: Does M have an odd gait when running?

Parent: Yes he has a very peculiar way of walking and running. I cannot describe it! He looks so skew and out of balance most of the time, never straight - not even with Kung Fu.

Researcher: Can you describe M’s sense of balance?

Parent: His balance seems to be fine but probably all the skateboarding and bike riding must have helped.

Researcher: Does M have a decent sense of rhythm?

Parent: M might walk slowly, but he loves to dance to music. He manages quite well to follow the new Rap dances and movements he copies off the television.

Researcher: Does M tend to rock back and forth?

Parent: M does not rock at all. He just talks non stop and moves a lot, moves this way and that way and up and down. But he is not that bad. It definitely gets better when they get older. He gets his active moments, mostly between 6 and 8pm at night.

Researcher: How would you describe M’s handwriting? Does he have a bad handwriting - if so, does this cause trouble in class when his teachers perhaps complain that they cannot read his work?

Parent: When M was on Ritalin his handwriting was beautiful. Now that he is off Ritalin his writing is terrible and he is very slow. I do not mind as I refuse to put him on any medication. He has never been punished for his handwriting. The fact, however, that he works and writes so slowly could become a problem. He often mentions that he struggles to write everything off the board so quickly and there are always notes from his teachers saying, “please complete” which proves he writes too slowly.

Researcher: You said M was on Ritalin - and it helped with his handwriting - why was it prescribed, did it help and if so why does he still not take it?

Parent: M was on Ritalin (schedule 7 drug) to help him concentrate, but the Ritalin had a side effect which made him depressed so he had to take another schedule 7 drug (anti depressant) called Aropax to help him with the depression which was caused by Ritalin. It seemed that when the Ritalin started working out during the afternoon the depression started during the evening. As a result I had to give my child two schedule 7 drugs per day to counter for the side effect of the other one. The Ritalin (no matter how small the doses were) still made him dizzy at times and with all the drugs he ate extremely badly (hardly ever). To test the drugs, I took Aropax one morning and at work I also started vomiting and I felt sick the whole day - so if this is how I felt, how was my child feeling? I had to make the decision whether I wanted a child that concentrates and does well in class (fits in) or an unhealthy child. I made the decision that M's health was far more important to me. I wanted a healthy eating, happy child, even if he was going to be a slow child at school.

Sensory sensitivity

Researcher: What about M's food dislikes and likes - does he have good eating habits?

Parent: M is very particular with his eating habits, he does not eat around. He has a set menu for the week and does not like eating anything else except what is on the menu. He does not like experiencing with food - he sticks to what he knows. The same with clothes.

M has a new thing - he checks the expiry dates on every single thing before he eats it, and then he reads the labels on any cool drink and tells me that he will not drink it because there is acid in it. I told him that I check expiry dates when I buy things and he does not have to worry. I also told him that if he does not want to drink or eat things with all the colourants and flavourings (I think the ascorbic acid puts him off as he probably compares it with real acid!) he is going to die of hunger because most things have this in. I also explained to him that he does not have to worry because we eat a lot of vegetables and fruit and a little bit of colourings will not hurt. I said that luckily we do not eat chips and drink fizzy cool drinks e.g. Coke. When M was first diagnosed with ADD I already had him eating healthy.

Researcher: Does M withdraw when you want to touch or hug him?

Parent: No he **LOVES** hugging and kissing from people he knows.

Researcher: Is M hypersensitive towards the feel of certain types of clothing?

Parent: Absolutely, if he does not like the material he will not wear it at all. I usually buy him three of the same shirts or pants if he likes the feel of the material. For example if he

likes one particular kind of pants I will buy five exactly the same because he will only wear that one pants even if there are ten other pants in his cupboard. He likes everything the same, same food, same clothes.

Researcher: Is M hypersensitive towards loud sounds?

Parent: No, he is not sensitive to sound when we are alone but definitely gets distracted in class if other kids shuffle or move around - these kinds of sounds distract him.

Inclusion

Researcher: Have you perhaps heard about the new 'inclusive' policy whereby all learners should be included in the regular classes? What are your feelings towards inclusion?

Parent: Inclusion can work if there is special training for teachers! My child has an average to above average academic performance thus he cannot go to a special school. But socially, he does not fit into a regular school either. He gets A's and B's but his behaviour is atrocious if not understood or treated correctly. In grade 6 he obtained the following marks: English- 64, Mathematics- 70, Afrikaans- 77, Science- 72, History- 76, Geography- 77, Health- C, Art- B. His final percent was 73. So as you can see they are all B's almost A's!

Try and get some information from a teacher in a public school, chances are they will not know what Asperger's Syndrome is. The problem with most of the learners with specific problems is that most of the teachers do not understand them. They do not read the information given to them by doctors or by the parents and their diplomas or degrees do not tender for all these disorders. Teachers are also so pressurised and have far too many kids (over forty) in their classrooms. M was fortunate last year in the private school where there were only twelve kids.

Researcher: I was wondering when you said that M is fortunate to have attended a private school with only twelve learners in the class. Do you think that this has made a difference to his inclusion in the regular school? Has he ever been in another school or has this been the only school he has attended?

Parent: M has always been in a government school. In grade one his teacher already realised he had a problem. He repeated his grade one year in an Aid class, and the teacher there was terrific, it gave him a lot of confidence. He went back to a normal grade two class. He was in an excellent primary school. They all knew him, understood him, and accepted him even if it was not easy for them.

Then we moved when he was in grade four. He went to this government school which was disgusting and very unaccommodating towards him. I had all my days with this school as you will read from the letters I wrote to them. In this school the classes are over full and the teachers very stressed.

I then sent him to a Christian School last year, but he also only lasted there for four months because he pushed the principal's son. I then sent him to this private school but he was only there last year (for grade seven), because I cannot afford a computer and they follow the Advanced Christian Education syllabus (ACE). He is now in an Afrikaans Technical High School, because I refuse to put him in an English school again, they are too full. He will probably suffer extremely being in an Afrikaans normal school again. I just take it day by day. I'm already seeing signs of him running into trouble - he does not understand how his roster works or how to pack a roster (this is where too much change is bringing confusion again). I see him bringing home loads of work already as he is too slow to write off the board, I also see him not understanding the Afrikaans, so I translate everything. I think the teachers consider him as new and confused but by the second term they will probably start picking up that there is a problem.

Society

Society adapt to specific learner's needs

Researcher: Do you think that society is causing difficulties for your child to be accepted, for example by labelling and wanting your child to change instead of trying to change to meet your child's needs?

Parent: What is normal? According to M, he is normal and everybody else seems to have a problem. I think it's a difficult statement to say that we should fit in or they should fit in. We lack too many resources (e.g.) for blind children or deaf children to go to "normal" schools. It would be nice if we were just a little bit more considerate and caring regarding people with any disabilities but that is our moral standards and as we all know some people lack some moral standards. We have to teach our kids at home to be considerate towards people less fortunate than us. This is a nice verse I stuck up at work and gave to M :

"Every colleague, as a human being, is of equal value to you, seniority in age, rank or education does not translate into MORALLY BETTER. It just means that you are DIFFERENTLY qualified".

I think these children should be able to adapt if they get the necessary attention and support from the teachers. This however is becoming more and more impossible due to the enormously large classes.

Blamed for bad parenting

Researcher: Before the diagnosis, were you ever blamed for bad parenting?

Parent: **ABSOLUTELY**, all the time, by his school, family and friends.

Respecting diversity

Researcher: Do you feel that M's differences are respected in society– for example is his teacher willing to change to accommodate any differences that he may display?

Parent: I find the teachers the least bit of understanding. I seriously just think it is because they have NO idea what Asperger's Syndrome is, they have never been informed, and are also not interested. My sister-in-law, a teacher, said, "I don't have time for 'such children' in my class, I leave them behind and carry on with the 'clever' children, I am not a psychiatrist, I cannot see why 'these' kids should be our problem etc. etc."

I would say children are more understanding, especially in his age group now - teens, probably because they all feel out of place in anyway. The teachers are the least respecting. His EMS teacher said he can understand Afrikaans but he is just sitting back - I tested him and found that he still does not understand Afrikaans fully, e.g. he said a "Regering" is a Municipality, a "Staat" is a "street", when his teacher stamps "voltooi!" he thinks it means "finished" instead that it still needs to be completed etc. I cannot even bother arguing with her. I always feel if I have just ONE teacher on his side then we are going strong, his register teacher likes him but now that teacher is leaving to another school, pity! I have to admit, when you go to parents evening you can immediately see who the genuine teachers are and who the teachers with an attitude are. I must be honest and say in this school most of his teachers are absolutely sweet and friendly and I respect most of them, out of the 8 teachers there is maybe one or two whom I do not trust. However, I do always take the teachers side in everything they say even if I do not agree with them - if they say M is sitting back then I tell him to stop sitting back, I take their word for it that he can do better.

The children in M's class are very supportive to him, it's as if without even telling them, they realise he has a problem. I find that they help him all the way - go here M, do this M, this is what you must do M, this is how you must do it M. He had his first Afrikaans school friend yesterday, and I was so impressed. I listen to M and I think he is so strange, what must his friends think, but it is as if they do not notice or else they are VERY patient. M was bragging yesterday, "I'm so good at this game, and I'm the best skateboarder, and I have such a lovely room, and I have such a good attitude." I was just listening to him boast to the friend and feel it's because I always tell M these things and tell him to have a lot of self-

confidence. Now I have to explain to him that he should still have confidence but that his friends might see it as boasting. I have to teach him a different way of **SHOWING** confidence and not **SPEAKING** (showing off) confidence.

If it was not for me I doubt anyone would focus on M strengths and abilities. I make everybody aware of his strengths; I make him aware of his strengths. At least my parents are the same, I educate my mom a lot and she explains to the neighbours. In this way at least a few people love M and I keep M among these loving people.

Teachers positive attitudes essential

Researcher: Do you think that a teacher's attitude (either positive or negative) has or is making a difference towards the acceptance of your child?

Parent: The school always depends on the teachers' and the principal's attitude with kids with learning disabilities. We will play one day at a time.

M used to enjoy Afrikaans because he liked the teacher and said that she explains the work clearly. Then one day she sent him to get a letter because he was talking in the class - he now cannot stand the teacher because his perception is that she punished him because she does not like him so why must he still like her! I tried to explain that she has forty other kids in the class and that it's frustrating when you talk in her class. I totally explained the teacher's point of view, telling M that he IS wrong and that he should be sorry - he does not understand this, she does not like him; end of story.

Funny how he would enjoy Afrikaans, even though it is a subject he finds difficult because the teacher is nice, shows you it still makes a difference! Pity this has now changed.

About people's attitude, I feel if he cannot change then peoples' attitudes dealing with him has to change. We can change, they cannot.

Support Networks

Easy to cooperate with teacher

Researcher: Is it difficult for you to work together with M's teachers or any other person involved in his education?

Parent: I was so involved with M's education but whatever I suggested at school or tried, they refused, they wanted to do everything their own way. I have also learned with M. So you see it has not always been easy to cooperate with his teachers and often they just would not care to listen to me.

Parent involvement and empowerment

Acceptance when first diagnosed: mother

Researcher: What was your first reaction when you first found out that M has Asperger's Syndrome?

Parent: **EXTREME** relief, I could never understand why he was so eccentric. M and I have had no contact with his biological father since my pregnancy. His biological father is extremely intelligent, he was a lawyer but chose to use his talent to imbecile money and was taken off the lawyers' role. He is, now, somewhere in Ramsgate. I chose not to have contact with him, as he was never interested in us anyway. Unfortunately I have been married twice since then. Men do not understand it at all. Both the men I was married to could not understand why I was spending so much time with M. I spend two hours after work with M and that is just helping with homework, so you can understand that it puts a lot of pressure on any relationship.

Parent knowledge of the syndrome

Researcher: Have you had any specific training in how to deal with M?

Parent: No, only what I read myself through the Internet and books. I have also learnt from attending the support group. The support group is very small, about 13 people. I benefit from it because the material I read from them helps me to understand better, and sometimes just the social. It helps to listen to people who have more or less the same problems.

Essential for parent involvement in school life

Researcher: With the new inclusion policy, parents are required to be very involved in their child's education and cooperate and be a major form of support - do you think that this is a good policy?

Parent: Like I said, I was so involved with M's education but whatever I suggested at school or tried, they refused to listen. I think it is important for parents to be involved in their children's education but not too involved. I realise, I might have made a mistake and should not have been so involved at school. I should give him the support at home, but you know it's so difficult not to be involved when people are hurting your child or unnecessarily punishing him.

In his new school I did not even tell them he has Asperger's Syndrome because I'm so scared the teachers and the children are going to be prejudiced, as all in his previous school were! If I get a call from school when they start picking up strange behaviour, I will ask for a teacher to speak to whom I can trust and will understand. M is already talking a lot about a

Mr.T, if he mentions this teachers name so often I get a feeling that this is the teacher I would ask to speak to should they realise M has a problem. First I want to give M a fair chance like any other 'normal' child.

Classroom assistants

Researcher: Do you think that if M were to have a personal aide with him throughout the school day, he would cope and perform better in the regular school?

Parent: There are really no personal aides that can help these kids, except a teacher who specialises in learning disabilities and behaviour associated with these disabilities. Only these teachers will understand that these kids learn better with routine, they hate many changes in class and many different teachers, and they get confused.

As I said qualified teachers, smaller classrooms, A LOT OF PATIENCE.

Community based support

Researcher: Have you ever noticed if any of your child's teachers have utilised assistance from outside the school boundaries – for example, people in the government, business, commercial sectors and so forth. If so, have these proven to be worthwhile?

Parent: It's difficult to answer for the teachers as I really do not know how or what they do in class. However, I am almost convinced that they do not utilise any outside sources. Teachers are not interested in attending Asperger's Syndrome meetings or receiving information which I print them nor are they interested in speakers at their school regarding any learning disabilities - I have tried all these before. I feel that if they were only interested in a little background or information they would understand better.

Curriculum

Researcher: Have there been any particular teaching methods, which have really helped M (for example, social stories, cartooning, videos and so forth)?

Parent: Only my love and patience!

These children really need one-on-one attention all the time or much smaller classrooms. I spend two hours solid in helping M every night with homework, what does a teacher do with forty kids in a class, if this is the attention I'm spending on one child.

I have never heard or seen comic strips or social stories that can help these kids but one thing I can ASSURE you is that teachers are not interested at all - they have enough to cope with.

With forty children in a class, never mind children with learning disabilities, they are not equipped nor interested either. These children really have **NO WHERE** to go.

Flexible curriculum

Social skills training

Researcher: Do you think that social skills training should be introduced as a subject in the school curriculum?

Parent: The biggest problem an Asperger's Syndrome child has is social. It's really a pity they do not teach these kids social skills at school. Instead of an art period, maybe put in an extra social period. He has to learn to be social, if I want him to work one day. The tougher it's now the easier it will be in later life. That is why I'm trying mainstream for M again. I feel that in the private school where he was last year, and at home, he is too protected.

Some useless subjects found in the curriculum

Researcher: Do you feel that there are subjects which are taught at schools which are in actual fact a waste of time, can you give examples?

Parent: Certain subjects (and parts of subjects) do not interest M at all and could be left out of the curriculum (like history). He has a subject at school that he enjoys called 'EBW' – the Afrikaans for 'Economic and Management Science'. It's about economics, starting your own business etc. - he enjoys this subject as it leaves him room for his own imagination, (no set rules). Afrikaans is difficult, it's almost like Shakespeare, and makes no sense to him. Like poems, Afrikaans does not say things the way they are. He is enjoying the workshops at the moment. M loves the subject Life Orientation because it teaches you more about yourself, self-image, your frame etc! Subjects like History and Geography do not interest him, but subjects like Science interest him.

Outcomes Based Education

The effectiveness of OBE and group work promoting education

Researcher: Have you heard of Outcomes-Based Education? Do you think that this is helping your child cope in an inclusive school?

Parent: OBE will not work for M. He can't even play cricket in a team, let alone do projects in a team. When M had projects to do, I'm not even ashamed to say that I did all of them. He cannot co-ordinate his own work, how can he co-ordinate with other children - they will also end up doing all the work and M will just follow. He is a follower and not a leader. In the OBE environment he will learn nothing but merely follow what others are doing.

I am hoping that a technical school where he will be more interested and busier with his hands, will make it easier for him to work independently. My child is not a team player at all, remember their social skills are ZERO!

In the private school he got that private attention which made him do extremely well. He did not have to follow all the rules schools have - 1100 rules of etiquette, e.g. stick up your hand and wait your turn if you want to ask a question. In the private school he could just go to Uncle Anton and ask. These children find it extremely difficult to wait their turns. They are very forgetful and need answers immediately before they forget. They also followed the ACE system which was excellent for any learner such as M.

Researcher: Can you describe this system that he followed last year?

Parent: It is a type of school program they do on a computer, a sort of a self-teaching program. The kids write diagnostic first to determine their academic level and then they are placed at the level of their understanding. They work at their own level, slower in those areas that they struggle and faster at their stronger subjects. Learners with special needs can use this system fruitfully. They get different books (for the various subjects) and then they have to work on their own by reading the books, answering the pre-tests, and other questions. When he is finished reading and studying the book he gets an empty test with questions. He must write a test after each pace. He then also has to score the test himself. Afterwards the principal will check that he has scored correctly and if he can carry on with the next pace. They have to pass every pace (book) with a 90% average, and then they move onto the next pace. This is a good system as he works on his own time, but he also has to set goals for himself so he cannot work too slowly. From what his principal has explained, for such a system to work, the children would only succeed if they have the ability to work on their own.

Assessment

Researcher: Have you heard about the different forms of assessment in OBE?

Parent: I'm not aware of the different forms of assessment in OBE. If the teachers are using new forms of assessment, I doubt it is working for M - I have seen him get 4 (excellent) for his exams (84 - 90%) and then a 1 (not achieved) for certain class work which I do not see. These 1's bring down his marks so tremendously that he fails, and this is where participating in the class or speaking in front of the class or whatever they are doing is not helping M at all because they are unaware of his problems with socialising skills. I once asked a teacher why he received a 1, and she just mumbled about a graph or something he had to do in class. As parents we have absolutely no information as to what goes on in the class at all.

Visual Aids

Researcher: As mentioned earlier learners with Asperger's Syndrome are more visually oriented. Have you or any of his teachers attempted to utilise visual aids when explaining things to M?

Parent: I doubt they have visual aids or role play either. A pity, because these kids need a lot more visual aids, pictures to explain what is expected of them. For sure, they need a lot of role-playing to explain feelings, or sentences like, "pull up your socks, don't dig up the past. Taking something from someone should be role played to explain the emotions involved of having someone do it to you, how you would feel etc.

Researcher: What are your feelings about computers in education?

Parent: Computers in education are excellent but not all the classes and certainly not for the whole day.

Researcher: Will your child respond to computer-aided instruction? In other words, if certain lessons were presented on computer?

Parent: M will respond to computer-aided instructions if the class is interesting. He actually thinks that computers, the normal 'Word' lessons are boring though. It should be given in an interesting, game kind of way so that his attention can be captured. He likes 'Paint' on the PC as well.

Researcher: Finally, is there perhaps any other information which you would perhaps like to add which has not been covered by the above questions?

Parent: M is extremely loving, sharing, very honest, loves to be praised, draws beautifully and drives himself, (for example, his school work). I believe in angels and my child absolutely has angels, the doctor who diagnosed him with Asperger's Syndrome and the principal at the school where he was last year are his angels. Since he has been diagnosed I have had just pleasure in my life and full understanding. M is now free of medication. He took Ritalin to cope in a regular school and the Ritalin made him depressed so then he took anti-depressants, he was constantly dizzy and not eating and miserable. Since I put him in a private school and his principal and teacher at school love and accept him, he has gone off Ritalin and anti-depressants and is generally happy and healthy! Time will tell now if he is accepted and how he copes in the mainstream again.

