From the Inside

Raising, teaching, loving an autistic child

(2nd edition – revised and updated)

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This book is free but any donations would be most welcome and can be made through PayPal at nvandokkum@wit.ie

♥

Acknowledgements

The most important player in this entire saga stayed mostly in the background. A reassuring presence, a sympathetic ear and a constant source of support: my husband, Neil. His background role was vital. He worked all the hours we're given, and then found some extra hours no one knows about and worked those too, all to earn enough to pay for Ian's therapy programme. Lecturer, Mediator, Barrister, Author, Neil poured himself into his many jobs and somehow held it together for the rest of us. And still he managed to be a hands-on father and a loving husband.

My love and gratitude know no bounds, my special man. Until the end of time and beyond.

To the three therapists who worked so hard for us and with whom we are sadly no longer in contact, I hope you know how much you were – and are still – appreciated. We couldn't have done this without your help.

To Kirsty and Antoinette, my friends, my secret-keepers.

Kirsty, you have been with me all the way through. Your guidance and honesty have been unfailing. I would never have lasted the distance without your support.

And Antoinette, for believing in me, for believing this was a story that deserved to be shared, and for pushing me just enough to make sure I get it published.

I thank you both from the bottom of my heart.

Chapter One

Ian was born by Caesarean section at around 2am on the morning of November 24th, 1995, in Durban, South Africa.

The Caesar was elective.

There was a good reason for this: the birth of my first child was just plain awful. That time, after hours of induced labour and many and varied efforts to push the unmoving child out into this world, I was exhausted. All I wanted to do was sleep. And perhaps if I stopped breathing and died, it would all go away …

And then I heard my husband’s voice in my ear – “Breathe, dammit! Breathe!” – and I was brought back to the bone-wrenching pain, and realised I couldn’t die just yet.

Later, with the Gynaecologist in attendance, things had taken on a more clinical appearance. I was no longer the Earth Mother pushing her baby easily into the world without help; I was a woman in danger of losing her life, and that of her baby, too. I remember the Gynaecologist snapping at me - “Shut up and push!” - and a variety of terrifying-looking metal implements; and then, after one final gigantic heave which ripped a primal howl from my throat, my first child was dragged reluctantly into the world.

So we wouldn't be doing that again.

Pregnant again before my son's first birthday, my second pregnancy was as easy as the first, and I loved it. I wanted to be pregnant forever! Nothing in the world compared to the feeling of a child moving inside my womb. It made me feel utterly complete. However, I had a nagging feeling of disquiet, without being able to pinpoint exactly what the problem was. One evening, we watched a particularly harrowing episode of 'E.R.' after which my husband looked at me with a terribly worried frown, put his arms around me, and asked, "Couldn't you have a Caesar this time?". Of course the birth of our first child was sitting on my mind! How could I not have realised this? I discussed the matter with the same Gynaecologist who remembered very well how it had been for me the first time, and it was all arranged. The weight was lifted from my shoulders and the remainder of my pregnancy was a breeze.

Ian was born in the small hours, safely, clinically, and easily. Less than an hour after he had made his mewling appearance, I was sitting up in the ward bed holding him in my arms as he slept. I looked at his perfect face, which glowed as if suffused with some inner light, and said quietly to him, "Welcome to the world, my child. You are my little angel sent from heaven just for me."

I knew nothing about autism at that stage, of course, but Ian wouldn't breastfeed properly – although I had enough milk to feed every child in the maternity ward – and I began bottle-feeding him when he was only five days old. I look back now and I think, How weird that he created a distance between us, even then.

Ian slept well, right from his very first night. After a first child who had only slept in 10-minute snatches for eighteen long months, a sleeping child was new to me and slightly disconcerting.

"Should I wake him?" I asked the ward sister, having watched Ian sleeping for six whole hours.

"Oh no," she reassured me, "He's doing brilliantly. Just let him sleep."

So I watched him some more. Mostly he slept in my arms or on my chest, fitting there so perfectly and sleeping so soundly that I never wanted to let him go. He didn't cry when he awoke, but woke up slowly, taking in his surroundings. When I think about it now, I struggle to remember him looking directly at me in those early days, but then I'm sure he must have.

I still maintain, though, that Ian was always autistic. That he was born autistic. There was never a time of regression because there was never any real progression. His milestones were on the late side, but not worryingly so. He played deaf, but we knew he wasn't. He looked at us frequently, but on his own terms. When we played the fool he gave us a look of such contempt, we couldn't help but laugh. He wasn't entirely quiet but there was no speech at all. We were convinced of one thing, though: He was most definitely not stupid.

But by the time Ian was a year old I said to Neil, "Ian is slow", and he hugged me and reassured me that we should wait longer and see.

By the time Ian was two, I was asking the paediatrician some serious questions. There was still no speech at all, and Ian's refusal to join in our lives was becoming more and more marked. The doctor's response was that he felt Ian was heading the same way as his older brother – ADHD – although via a different path. This was reassuring in its way, but I still wasn't convinced.

Six months later I had had enough. I faced the paediatrician, frustrated and angry.

"Today you will tell me what is going on with my child."

And he sighed and said, "This isn't my area of expertise, but I strongly suspect Ian may be autistic."

It's extraordinary, in retrospect, how you can hear news like this and just smile, say "Thank you", and walk away, holding the hand of the little child for whom a life sentence has just been pronounced.

My little angel sent from heaven.

He still smiled and gurgled, and accepted hugs and curled into our arms like an affectionate little bear, but now everything was different and would never be the same again.

Chapter Two

But I must go back a little further.

Neil and I met at a wedding in Durban, connected instantly and, as I lived 1,000 miles away in Cape Town, courted by letter and telephone call. It seems hard to imagine today, I'm sure, with all the advances in technology that have taken place over the past twenty years, but it worked for us. We met in April, were engaged by July, living together by September and married the next January. Already in our thirties, there didn't seem any point hanging around and besides, it was most definitely meant to be. Our first son, Rory, was born just over a year later.

Rory was a very 'finished' baby. He never really looked newborn. He had golden skin, black hair and black eyes that observed the world from the very first moment they opened. I came from a family of fair-skinned, blonde, blue-eyed people and I somehow imagined that my child would look the same. He was like a changeling to me. After that difficult birth, it took me three months to bond with him. To this day I remember the exact moment: a 2am feed, lying in the near-darkness with this solid lump in my arms, looking at his round cheeks and rosebud mouth, and suddenly feeling overwhelmed with love for him.

When Ian arrived Rory was 18 months old, and he was delighted with his sibling. However, for us, those were the easy days. As he grew, Rory became more and more difficult, and as he approached the ‘terrible twos’ his tantrums grew into the stuff of legend. He could be heard screaming from one end of the shopping centre to the other. And he couldn’t be reasoned with, distracted, cajoled, or loved out of it. When he went over the edge, he was in freefall.

It is extremely difficult to maintain a loving relationship with a spouse in the face of that. As the sparks flew off Rory, it was hard for Neil and I not to be infected by his anger. Sometimes we just sat holding hands, too exhausted to speak. I remember wondering what on earth I had done in a past life to deserve *this*. Rory destroyed everything in his path, found it impossible to sit still even for a mere moment, fiddled with everything he could reach, and he hit, bit, toe-walked, and *screamed*.

Throughout this difficult time, the person who understood best was my mother-in-law, Rory’s gran. Her first son – Neil’s older brother – had been the same as a young boy, and sharing ‘war stories’ with someone who truly understood was a great help to me. But it wasn’t enough.

Finally, when Rory was two and a half, I went to a paediatrician, sat exhausted opposite him, and said those few words I never imagined would come from my mouth : “Help me. I can’t cope with this child.”

He sat back in his chair and watched Rory fiddling his way around the room.

“Have you heard of ADHD?” he asked me.

Yes, I had.

“Well, your son has it,” he said.

“Okay. What do I do?”

“Medicate,” he replied.

“Goodbye,” I said. And I grabbed Rory’s hand and walked out.

A week of hell later, I was back with Neil. “Talk to us,” I said.

This gentle doctor then said words to me I have never forgotten and that became the mantra by which we lived from that moment on.

Life lesson number one: “*We need being happy to become Rory’s life habit.*”

It made absolute sense. His life habit. How perfect.

So we medicated, and within a week our lives changed. It sounds so melodramatic today, but it was true. Within that first week, I heard Rory laugh – something I hadn’t heard since he was a tiny baby – and by the end of that week we were beginning to understand what he was saying. Before the medication, Rory’s brain had been going so fast and his thoughts were so scrambled he couldn’t form coherent speech. On medication, the gibberish became words.

At last! He slept. He laughed. He learned to communicate.

Several years later I learned that the Melleril Rory had been on was no longer available for children with ADHD – certainly in South Africa – and this made me very sad. All those angry children who could have benefitted the way Rory did; all those parents whose lives could have been improved by making happy their child’s life habit … It seemed wrong to me. Oh, I am sure there were good reasons for its withdrawal and I hope something just as effective has taken its place, but it changed our lives and I felt bad for parents whose lives weren’t being helped the way ours had been. Rory was on Melleril for four years. A tiny dose, just a teaspoon in the morning and again at night. After a year and a half, I stopped giving it to him in the morning, and towards the end of four years, as the final bottle emptied, I decided to try life without. It was a success. Rory no longer needed it at all. Happiness had become his life habit.

It wasn’t all plain sailing, of course. It never is. There was speech therapy, which Rory enjoyed, but when he was three and a half it was recommended to us by the pre-school Rory attended that he be psychologically assessed. Well, they weren’t particularly friendly about it; it was that or expulsion. So Rory attended a centre for special needs children for a proposed two-week period for assessment. It didn’t go well. He hated it there, cried when I took him and resisted going in, and before the end of the first week I knew things were going very wrong.

Life lesson number two: *Surrounded by other special needs kids, my child was imitating the disturbed behaviour of other disturbed children.*

I pulled him out.

The centre wanted Rory there, full time. They were quite insistent about it. I said no, and Neil supported me. We weren't prepared to write Rory off so easily.

Soon after that, we attended a School Expo where we wandered around, vaguely wondering what the future might possibly hold for our challenging firstborn, when I saw a stand for Roseway School (a school which followed the philosophy of Rudolph Steiner – the same as Michael Hall, the school of my own childhood). If we were looking for something different for our son, this might just be it.

Rory went to Roseway for three and a half years, from the age of four until he was almost eight, and he blossomed. There, he was accepted as the creative, determined, otherworldly child he truly was. I remember his very first day there – Rory was in tears at having to leave me, and his new teacher took him in her arms and hugged him tightly, looking at me over his head.

"I sense a softness here," she said in her gentle German accent, and I knew he was in the right place.

My two boys.

Rory tried valiantly to engage Ian and play with him; Ian ignored Rory completely. It was hard to watch. There was only eighteen months between them, but in many ways, Rory grew up as an only child. Ian was there but not there, an entirely self-contained unit that neither needed nor wanted the company of anyone else. They did play together sometimes, but it was more a case of parallel play, doing the same thing at the same time in approximately the same place.

When Ian's therapy programme started, our lives revolved around that and we knew Rory felt left out. We worked hard to include him in other things. When he was home from school, and while Ian was busy with his tutors and before Neil came home from his long work day, Rory and I baked together, and drew pictures, and made puzzles, and played with Lego and swam together in the paddling pool. To our enduring joy, Rory laughed a lot and seemed content.

Thinking now about the rest of the family, I wonder about the effect of Ian's diagnosis on them. There was no wailing or gnashing of teeth. There were actually very few questions. Ian was Ian, and he was accepted and loved just as he was. Perhaps there was a quiet sadness behind the scenes, but it was probably always assumed that I had the loving support I needed and that I would cope.

Yes, and (mostly) yes … although I suspect that women who cope well cry a lot in private. I know I did.

* * *

Rory has grown up into a wonderful, even-tempered, beautiful young man. Those difficult early days are now very, very far behind us.

Chapter Three

That day, after receiving Ian's diagnosis, I got home and I went through my books. Trying to get a handle on ADHD had led to many trips to the bookshop, and we had plenty of material covering all developmental disorders, including autism. I read and nodded. It all fitted. There was no room for doubt.

When Neil came home from work, I told him the news. He gathered me into one of his wonderful, comforting hugs and we stood holding onto each other, dry eyed and stunned.

"Okay," said Neil, taking a deep breath, "what are we going to do about this?"

Such a small word, but it was one that held within it the strength of our marriage, the enormity of our commitment to each other and to our children. This gentle, quiet, strong, loving man said, "What are WE going to do about this?"

We looked at each other.

"Well," I told him, "the paediatrician has said we should contact The Browns' School [a school for special needs children in Durban] for a screening test and then, when we have their report, we should see a Psychiatrist at University of Natal, Durban, who will confirm the diagnosis. After that, possibly a Genetics specialist to see if there is any genetic connection, and then, who knows?"

A great big empty hole called The Rest of His Life still had to be faced, and in truth we had no idea how to do that.

The screening at The Browns' School was a strange process and the first of many times we would come into contact with good people who meant well but who provided us with absolutely no help at all. It revealed an approach prevalent within the health services which would leave us, time and again, feeling frustrated, alone, and more than a little angry.

We arrived at the school, and our immediate response on getting out of the car was a deeply negative gut reaction –

"Ian is *not* going to go here."

It looked austere and forbidding, far too much like an institution, even though the building was new and the windows were large and open. The gardens were well cared for and quite pretty. But there was an unsettling aura about the place, a silence that was watchful rather than peaceful, and we realised then that we were determined to protect our child from anything like this for as long as we possibly could. His whole life if we could manage it.

After a lengthy wait while they co-ordinated the various members of their screening team, we were shown into a large room. There were toys in one corner, and a couple of chairs where Neil and I sat. There were children's pictures on the wall, too, but the overall impression was drab, probably enhanced by the extensive area of hard-wearing office-type dull brown carpet.

Then the team members arrived and arranged themselves in a semi-circle of five chairs, an impersonal six yards away from us. There was nothing intimate or congenial about this get-together. There was a speech therapist, an educational psychologist, an occupational therapist, a remedial teacher, and the senior school psychologist, all with notepads on their laps and pens in their hands.

Ian wandered around the room exploring. Five professional heads turned to watch him. He admired his reflection in a mirror, and then went through a succession of toys, which he picked up and fiddled with, then chucked because they held no interest for him. With Ian thus occupied, the team asked us questions. I had taken my books to Browns' with me, the relevant pages marked so I wouldn't forget anything. I read out certain passages, and Neil and I explained their relevance in terms of Ian's behaviour. Occasionally Ian came back to me and I played with him to keep him happy, throwing him in the air and lifting him onto my shoulder, a game we had shared many times and which always brought delightful chuckles from him.

We were there for about an hour and then it was time to leave. Ian, now settled in this new place, didn't want to go and became distressed when we had to insist. Embarrassed but determined, we manoeuvred him out of the building.

Back in the car, Neil and I breathed a huge sigh of relief just to be away from that room. We were both quite shaken by our reactions to the school and sat quietly in the car for a long time, just holding hands.

After the meeting at Browns', we met with a Psychiatrist who seemed happy to confirm what we already knew, and the next day we met with the genetics specialist who agreed that there didn't seem to be any physical features which suggested a genetic abnormality. He was happy not to take the matter any further.

Having done the rounds of meetings, that appeared to be that. No one came forward with any bright ideas; no one offered help; no one seemed to know what we should do next. We found ourselves sitting at home staring at that big empty hole called The Rest of Ian's Life, floundering.

Weeks went by. Nothing changed.

Then I came across Catherine Maurice's book, Let Me Hear Your Voice, in a nearby bookshop. It was expensive and after a brief glance I had put it back on the shelf. I browsed around the shop, went back to the book, picked it up, and looked at it again. Somehow I knew this was the book we needed. I decided to buy it.

It was only after I had read it from cover to cover that the enormity of what we faced really sank in. Alone in the spare room with the finished book in my hands, the numbness I had been feeling deserted me and I howled silently, tears pouring down my face.

"My son is autistic … my son is autistic … my son is autistic…"

I couldn't stop the words ricocheting inside my head.

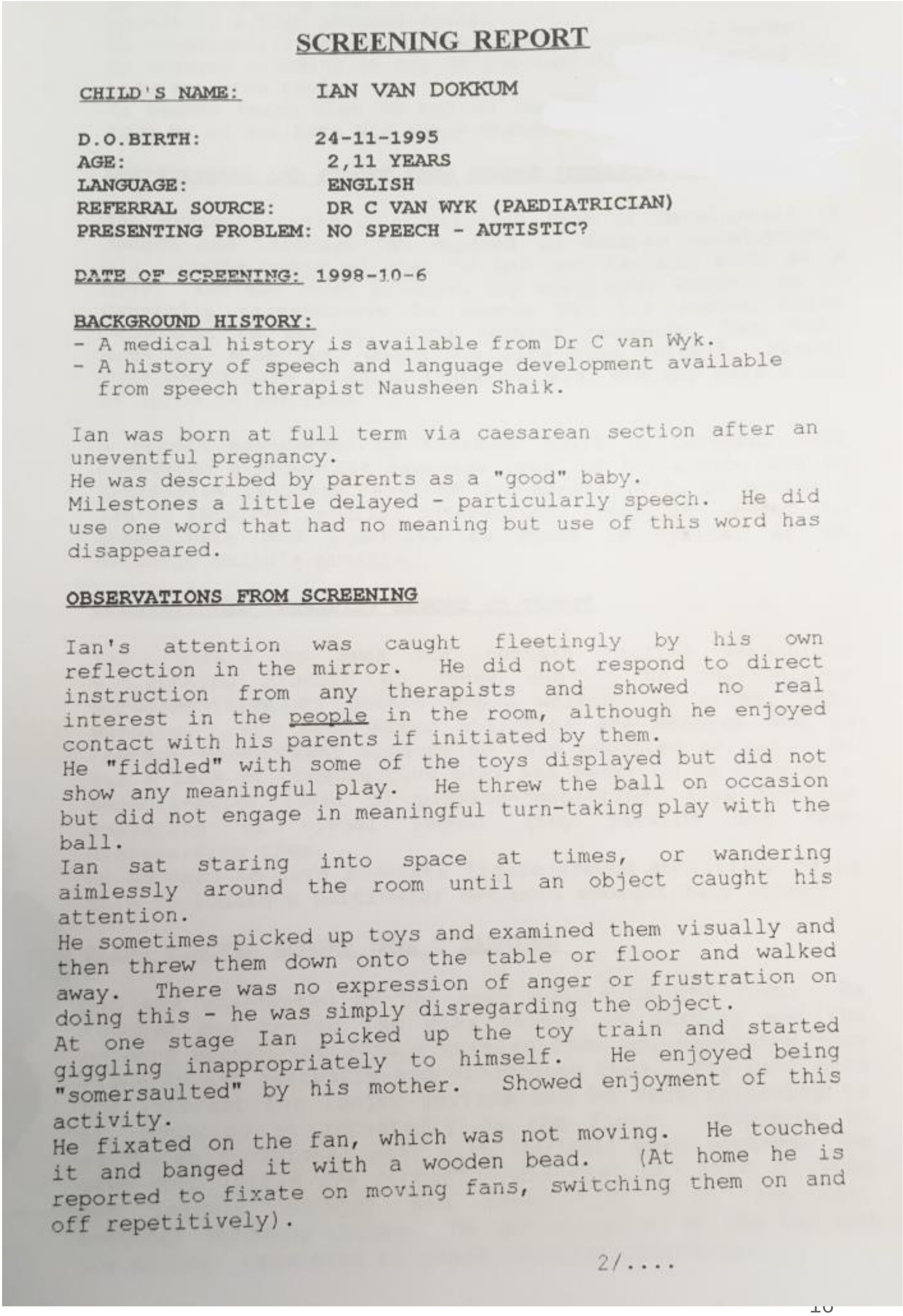
On and on I cried, alone in that room, until my fighting spirit reasserted itself. I may have been wounded but I was not defeated, and the message contained in the book I had just finished was truly inspiring. Here was a woman who had fought the fight, and recorded the process and her thoughts and feelings. It was an amazing book and hugely encouraging. When I emerged from the spare room I said to Neil, “You have to read this. Now.”

He read the book in one sitting, and then we sat down together and discussed how we were going to do what we now knew we had to.

Within the written report from The Browns’ School there had been one sentence, which stood out from the rest of the report. It had been written by the special needs class teacher, and said, “I suspect Ian has the potential to learn.”

This one single sentence was what we clung to, because we believed it absolutely.

* * *



SCREENING REPORT

CHILD'S NAME: IAN VAN DOKKUM

D.O.BIRTH: 24-11-1995
AGE: 2,11 YEARS
LANGUAGE: ENGLISH
REFERRAL SOURCE: DR C VAN WYK (PAEDIATRICIAN)
PRESENTING PROBLEM: NO SPEECH - AUTISTIC?

DATE OF SCREENING: 1998-10-6

BACKGROUND HISTORY:

- A medical history is available from Dr C van Wyk.
- A history of speech and language development available from speech therapist Nausheen Shaik.

Ian was born at full term via caesarean section after an uneventful pregnancy.
He was described by parents as a "good" baby.
Milestones a little delayed - particularly speech. He did use one word that had no meaning but use of this word has disappeared.

OBSERVATIONS FROM SCREENING

Ian's attention was caught fleetingly by his own reflection in the mirror. He did not respond to direct instruction from any therapists and showed no real interest in the people in the room, although he enjoyed contact with his parents if initiated by them.
He "fiddled" with some of the toys displayed but did not show any meaningful play. He threw the ball on occasion but did not engage in meaningful turn-taking play with the ball.
Ian sat staring into space at times, or wandering aimlessly around the room until an object caught his attention.
He sometimes picked up toys and examined them visually and then threw them down onto the table or floor and walked away. There was no expression of anger or frustration on doing this - he was simply disregarding the object.
At one stage Ian picked up the toy train and started giggling inappropriately to himself. He enjoyed being "somersaulted" by his mother. Showed enjoyment of this activity.
He fixated on the fan, which was not moving. He touched it and banged it with a wooden bead. (At home he is reported to fixate on moving fans, switching them on and off repetitively).

2/....

During screening Ian said no words and made a few odd sounds in a high pitched voice.
He occasionally walked on his toes or flapped his hands.
He enjoyed standing on top of the furniture or draping his body over the table.
He became teary when he had to leave the security of the room to go and have his nappy changed, or to go home.

OBSERVATIONS AND REPORT FROM SPEECH THERAPIST [redacted]

Ian presented with a significant lack of development of speech and language (as opposed to delayed development. His parents reported that he had not babbled much as a baby. Ian has never produced any meaningful words. He is generally unresponsive to speech but his mother noted responses to the following regular commands: "No, out, arms up, step out, would you like some juice?" Visual cues would help in these instances e.g. Mom may have a cup of juice in her hand.

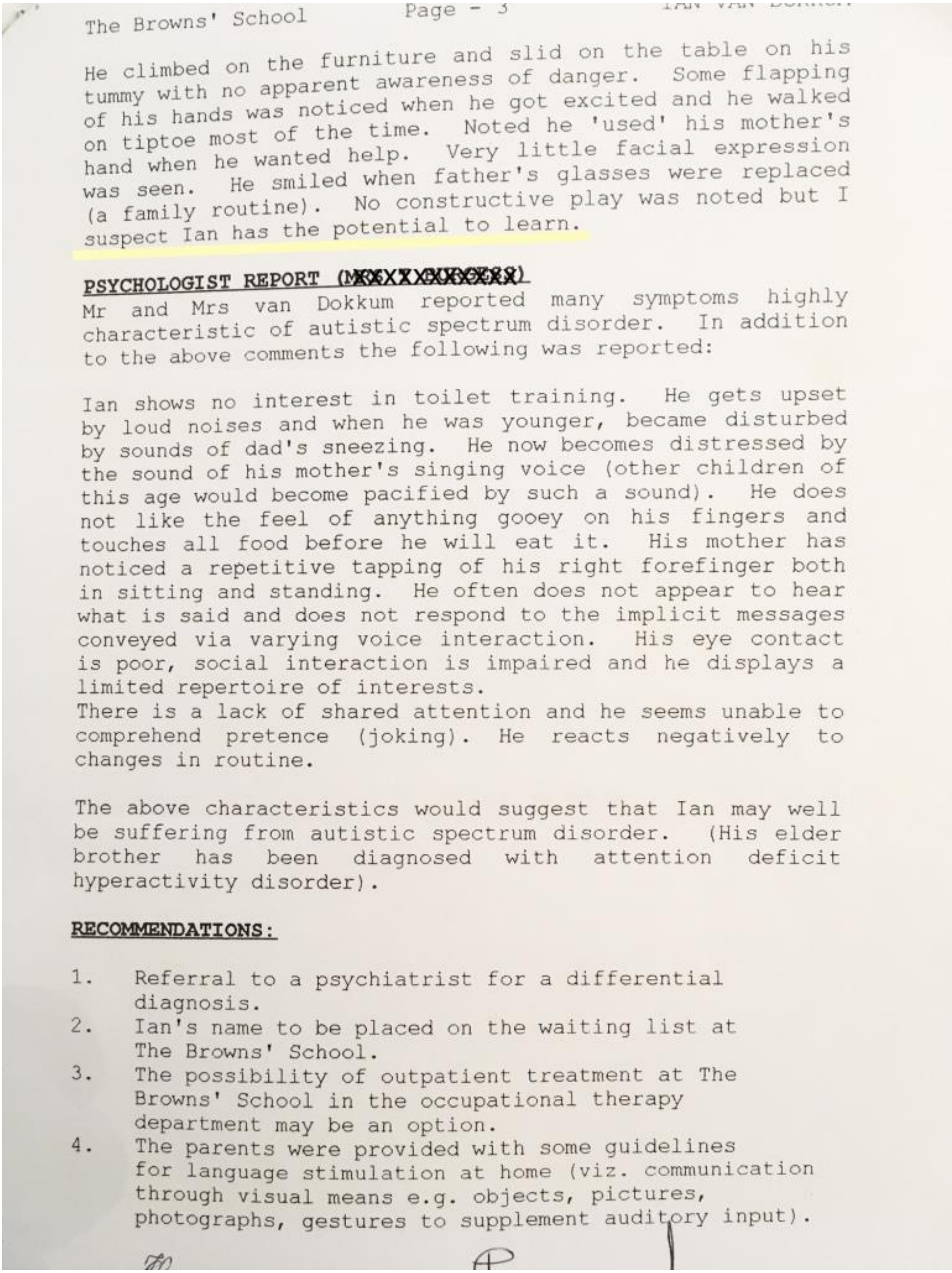
A speech assessment by Nausheen Shaik in December 1997 indicated a Receptive language level of 6-9 months and an Expressive language level of 3-6 months (C.A. 24 months). Ian's impaired social interaction; lack of intent to communicate and inability to speak is typical of an Autistic child's profile.

OCCUPATIONAL THERAPIST REPORT [redacted]

Ian appears to seek out certain tactile sensations e.g.rubbing biscuit on cheek and to be particularly hypersensitive to others e.g.. walking on grass, hair washing. His fine motor abilities are delayed and no concept development appears to have occurred as yet. He has a lack of constructive play and seems to be more on a sensori-motor level of playing-'exploring' toys for the sensation or visual impact they provide and then disregarding them.
He appears to have adequate figure-ground abilities, being able to locate a particular key/book amongst many others.

CLASS TEACHER REPORT [redacted]

Ian was unaffected by the many adults in the room. He touched and tested the play things on display and the objects around the room - picking them up, examining them visually and tactually and discarding them. The ball held his interest for longer periods and he kept returning to it, bouncing it repeatedly on the floor. Attempts to establish reciprocal play with the ball were ignored. He gave very little eye contact. His play was self-absorbed and largely sensory and exploritory e.g. feelings, banging, throwing things. He was attracted by the fan and the mirror, returning to these objects repeatedly.



He climbed on the furniture and slid on the table on his tummy with no apparent awareness of danger. Some flapping of his hands was noticed when he got excited and he walked on tiptoe most of the time. Noted he 'used' his mother's hand when he wanted help. Very little facial expression was seen. He smiled when father's glasses were replaced (a family routine). No constructive play was noted but I suspect Ian has the potential to learn.

PSYCHOLOGIST REPORT ([redacted])

Mr and Mrs van Dokkum reported many symptoms highly characteristic of autistic spectrum disorder. In addition to the above comments the following was reported:

Ian shows no interest in toilet training. He gets upset by loud noises and when he was younger, became disturbed by sounds of dad's sneezing. He now becomes distressed by the sound of his mother's singing voice (other children of this age would become pacified by such a sound). He does not like the feel of anything gooey on his fingers and touches all food before he will eat it. His mother has noticed a repetitive tapping of his right forefinger both in sitting and standing. He often does not appear to hear what is said and does not respond to the implicit messages conveyed via varying voice interaction. His eye contact is poor, social interaction is impaired and he displays a limited repertoire of interests.
There is a lack of shared attention and he seems unable to comprehend pretence (joking). He reacts negatively to changes in routine.

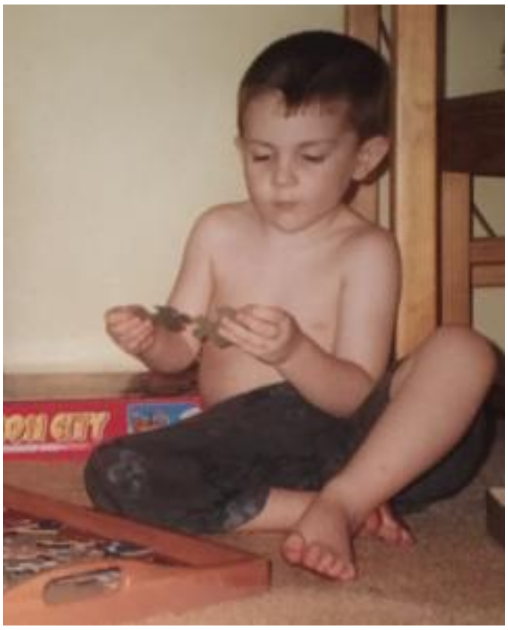
The above characteristics would suggest that Ian may well be suffering from autistic spectrum disorder. (His elder brother has been diagnosed with attention deficit hyperactivity disorder).

RECOMMENDATIONS:

1. Referral to a psychiatrist for a differential diagnosis.
2. Ian's name to be placed on the waiting list at The Browns' School.
3. The possibility of outpatient treatment at The Browns' School in the occupational therapy department may be an option.
4. The parents were provided with some guidelines for language stimulation at home (viz. communication through visual means e.g. objects, pictures, photographs, gestures to supplement auditory input).

The final page, showing the sentence we clung to.

Chapter Four



Ian was nearly three years old, hugely active, noisy but non-verbal, and isolated from the rest of the world.

In many ways at this stage he behaved exactly like a little animal – I don’t mean that in any insulting way, only that he acted like one. When taken into a new environment, he explored it in the same way a small dog might explore someone else’s house. He fossicked around. He nosed in corners. He looked, but he didn’t touch. He seemed oblivious to the humans around him, completely involved in his own mission.

There wasn’t much about Ian that conformed to typical child development except, perhaps, his acceptance of physical affection. Neil and I continued to hug him at every opportunity. (There had been a period when Ian was about eighteen months old when he tried pushing me away and refusing to be hugged, but I was having none of it. I hugged him anyway and within a couple of weeks he was accepting affection again. This has never changed.)

Knowing that we had to embark on an intensive home therapy programme, I read everything I could find. One book recommended making a list of all the things the child would do, things he wouldn’t do, and behaviours which should be targeted. This sounded like a good place to start and I sat at my computer, thinking.

What commands will Ian respond to promptly? Hmmm … I typed:

1. Out

2. No

What social behaviour will he perform correctly? Oh dear…

1. None

What antisocial behaviour does he indulge in?

1. No eye contact when spoken to / name called

2. Shrieking / wailing

3. Hitting

4. Throwing

5. Ignoring

Obviously our ‘little angel from heaven’ wasn’t quite such an angel …

And then I got down to the nitty gritty.

‘Manifest Autistic Behaviour’ – i.e. what did he do that the books cited as classic autistic behaviour?

1. Hand flapping

2. Shrieking

3. Withdrawing

4. Lack of response to commands

5. Absence of speech

6. Toe walking

7. Incessantly picking his skin

8. Hitting

9. Throwing objects.

Pretty much a full house then.

Did he have any appropriate behaviour?

Yes, sort of – he intermittently gave eye contact (although it was always on his own terms) and he accepted physical affection. At least we knew where we were starting from, and could pinpoint specific behaviours to target.

And yet, within this strange, difficult, non-speaking child there lurked extraordinary talent.

Aside from his fascination with the word 'Tuesday'; his strange visual acuity which enabled him to notice immediately when a book had been moved on one of our many bookshelves; and his ability to do puzzles upside-down – that's picture-side down, white-side up – I discovered quite by chance that Ian was cleverer than we had ever given him credit for.

One afternoon, I was sitting reading and Ian was playing with magnetic alphabet letters on the carpet. I looked up in time to see him placing three letters on the right hand side of the fridge door: 'X, Y, Z'. I grinned, thought *Yeah, right*, and went back to my book. He then selected more letters, so, curious, I stopped reading and watched him. Deliberately leaving a space in front of the X, Ian slowly put up T, S, R and Q, backwards.

I was frozen to the spot.

Then he filled in the U, V and W between the T and the X.

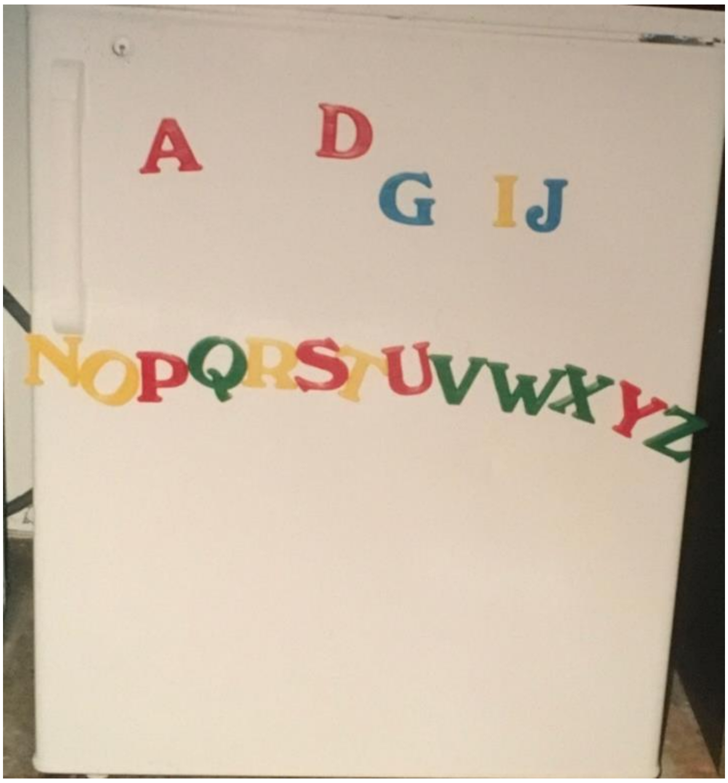
I had forgotten how to breathe.

Still going backwards, Ian placed the P, O and N before the Q and then ran out of fridge door. He got up, stood looking at his handy-work for a moment, and left the room.

N O P Q R S T U V W X Y Z. In perfect order.

I sat staring.

All I could think was, He *knows* the alphabet. *He knows the alphabet!* Bloody hell! He knows the alphabet *BACKWARDS*!"
Ian was not yet three years old.



A lucky photograph, taken at the time, of the fridge door with Ian's magnetic letters. (You can see quite clearly that Ian was lining up the beginning of the alphabet as well.)

Chapter Five

My first call was to the speech therapist at The Browns' School. At our meeting, some mention had been made of regular speech therapy sessions and filled with naive optimism, I telephoned the Speech Therapist to make an arrangement for Ian to see her.

To my horror, the best that could be offered to Ian was half an hour, once every two weeks.

Obviously, half an hour once a fortnight was not going to make Ian talk. Surely this was common sense? Stunned, I found I didn't know what to say next. How could the situation possibly have become so incredibly depressing so quickly? We wanted to set up an intensive home programme, including on-going intensive speech therapy, every day if we could get it, not twenty-six times – thirteen miserable hours – in a whole year!

She must have heard the disappointment in my voice, because the therapist then suggested I call her sister-in-law, Tania. Tania had been one of the Psychologists at our meeting at Browns', but she no longer worked at the school and was now in private practice in Durban and looking for clients. She had experience in working with autistic children. Perhaps she would be able to help us.

Taking Tania's number and feeling slightly encouraged, I ended the call. No speech therapist, then, but some help, possibly.

And then I remembered Nausheen. Because Rory had had a fairly severe speech delay, we had already been involved with a speech therapist for many months a year previously. Encouraged by my happy memories of Nausheen, I called and arranged to go and see her.

Sitting at a small table outside in the sunshine in Nausheen's garden, I outlined our situation and explained what we hoped to do. Then I asked if she would be able to help us. Nausheen sadly shook her head. She was about to go on sabbatical and was hoping to fall pregnant. She had too many other things on her mind to contemplate getting involved in something as intensive as the programme we were trying to arrange. My heart sank. Yet another dead end.

Then Nausheen brightened and said, "Hang on a minute. Maybe …" She had remembered someone she knew, another Speech Therapist, someone she felt might actually be in a position to help us. She gave me a name and number.

Regretfully I left. Nausheen had proved herself a special person whilst working with Rory, and I had been really looking forward to working with her again. But now I had two names and two numbers. It was a start.

Suddenly, instead of a great black nothingness, there was a pinprick of light at the end of the tunnel.

Neil and I set about redecorating a small spare room, which would become our therapy room. I painted it white from top to bottom. A plain colourless box. No pictures, no ornaments, no distractions.

Catherine Maurice's manual had, by this time, arrived from America. Within a week it had a well-worn look as I had read and re-read the early chapters to see where and how to begin.

I had the classroom, the tools, and the determination. All I needed now was the child.

I started taking Ian into the classroom every morning. He wouldn't sit, and he most certainly wouldn't look at me when I asked him to. You'd have thought I was asking him to peel his own skin! But there was nothing else in the room worth looking at, just an animated me, my brightly lip-sticked mouth encouraging and smiling.

After a few fidgety days, he did start to sit still for more than a few seconds at a time, and he did start to give a fleeting glance in my direction when I asked for it. Every time he looked at me when I said his name, my heart leapt, and I was encouraged to try again. And again. And again.

In other areas, Ian was making minute steps forward, too. I was determined that his education would not be confined to the classroom but would envelop his entire life. Expecting great things and sensing that it would be all too easy to forget where we had started, I began making notes of all the small improvements as they happened –

28th February 1999 – Taught Ian to tap the seat of the swing to show me what he wants.

5th March – Ian began to use pictures on the fridge to indicate that he wanted food.

10th March – Ian took his plate of food from me in the kitchen and carried it through to the dining room and set it carefully on the table.

18th March – Ian built a four-barrel tower.

19th March – Ian took his shorts off by himself.

20th March – Ian built a seven-block tower.

22nd March – Ian imitated me for the first time. He also helped me remove his t-shirt.

24th March – Ian climbed into his car seat on his own.

31st March – A block fell to the floor and, without prompting, Ian picked it up and put it back on the table.

1st April – Ian climbed out of the car, entirely on his own. Ian responded to “Show me horse” by reaching out to touch a horse’s face.

3rd April – Ian starts to smile back when you smile at him.

8th April – Ian allowed me to trim his nails without fuss. [This is a big one!]

11th April – Ian responds to “Show me dog” by reaching out to touch a dog.

12th April – Ian participated in the preparation of his juice, taking it out of the fridge, handing it to me, closing the fridge door while I poured, putting the juice back in the fridge and shutting the door behind him.

16th April – Ian completed a four-piece puzzle entirely on his own. At my request, Ian clapped happily throughout Oranges and Lemons.

17th April – Ian built a 10-block tower. I dawned on me that Ian no longer scratched or picked incessantly at his skin.

27th April – Ian imitates me imitating a cow.

29th April – Ian consistently imitates a vocal rhythm. Ian participated in a game of “Put on hat,” laughing and chuckling, and displaying appropriate turn taking.

Individually these might seem such small achievements, but to us, they were huge. Each event was a ‘first’ and was celebrated.

Ian’s education had made a very promising start.

* * *

Whether I do it here, or later, somewhere along the line I am going to have to explain our approach.

We didn’t go into this therapy programme to ‘cure’ Ian of his autism. We already knew that wouldn’t be possible – or appropriate. However, we did go into to it to deliberately modify his behaviour.

Partly because we lived in South Africa (where we knew Ian’s future would be severely impacted by his autism) and partly because we wanted to give him an opportunity to be the best version of himself he could be – and linking to us in a meaningful way would help him achieve this – we went along the therapy route with guns a-blazing.

At this time, there was no literature by adult autists explaining the (potential) trauma of an intense therapy programme, or the pain some have experienced by being forced to give direct eye contact. We had no frame of reference for things like this, one way or the other. We did what we believed was right – on the strict understanding that we would at all times be guided by Ian. If he showed any sign of distress, therapy would be stopped.

Chapter Six

Despite a complete absence of speech, I still had the strongest sense that Ian would speak, that he could speak, that somehow trauma or a severe shock would draw speech out of him. I sensed that he was so close.

Thankfully, Ian never experienced trauma or a severe shock. What he got instead was Ruth.

Hers was the number Nausheen had given me, and I had called Ruth straight away. We had a great chat on the phone, and she agreed to come the very next day. Tall and gangly, loose-limbed and delightfully relaxed, yet vibrant with vigour and energy, Ruth had short, dark red hair, green eyes behind red-framed glasses, and the widest smile I had seen in a long time. She arrived as subtly as a tornado and, entering our house, she made a beeline for Ian. Kneeling in front of him, holding him firmly by his upper arms, she bobbed her head this way and that, trying to keep her face in his line of sight.

“Hello Ian,” she said strongly and clearly to him. “I’m here to help you talk.”

Ian responded to Ruth that day the same way he would respond to her on many, many subsequent days : He ran away.

Poor Ruth! It was hardly flattering. But she was thicker-skinned than that and as a speech therapist with many years' experience dealing with adults who had suffered loss of speech through brain trauma or stroke, Ruth knew about forging new pathways in the brain. Over the following months she made good her statement and did indeed help Ian talk.

The fabulous Ruth

But on our first meeting, Ruth wanted information. She wanted to know exactly what noises Ian made and how often, and whether he had ever talked at all. She admitted she had never worked intensely with an autistic child as part of a team before, but she was more than prepared to give it a go. I told her about Ian's made-up word, which had been a favourite of his some months previously – "Dowidat" – and Ruth was greatly excited by this because that one nonsense word proved Ian could make vowel and consonant sounds. That one made-up word proved he had the potential for speech.

When I told her about Ian's fixation with the television guide and how he always turned the pages to Tuesday, I saw for the first time Ruth's intense interest in the potential Ian held inside him. She went still and quiet. "You're telling me he turns the pages by himself to find Tuesday, no matter whether he needs to go forwards or backwards, and he *knows* whether to go forwards or backwards?"

"Oh yes," I assured her. "He's adamant it's on the Tuesday page, no matter what page you put it on. And yes, if it's on Monday he goes forwards; if it's on Wednesday, Thursday or Friday, he goes backwards."

Ruth had been holding her breath but suddenly she exhaled in a great whoosh and flung her arms wide.

“Wow! Do you know what this means?” she cried, hopping around my lounge in excitement. “The little shit is *clever*!”

Our second find was Tania, who was the sister-in-law of the speech therapist we had met at The Browns’ School. She remembered Ian [from the assessment] and seemed keen to get involved in the programme. Tania was a slim blonde with china blue eyes, delicate skin and fine features. Now in private practice as an Educational Psychologist, she agreed to make herself available to us and had the experience we desperately needed. She was also the perfect foil to Ruth. Where Ruth was outgoing, talkative and quite mad (in the nicest possible way), Tania was reserved, calm and controlled. She agreed to work with Ian every single day, five days a week, and video footage showed that Ian always tried to give Tania his very best efforts.

The next member of our team came via Ruth who told me about a newly-graduated speech therapist who had been one of her best students. Anita was a young Indian lass with flawless café-au-lait skin, a slender build, dark eyes and long straight black hair. Ian was fascinated by her. He also sensed her lack of experience and exploited it mercilessly, making Anita work the hardest of all. It didn’t help that as the youngest member of the team, Anita ended up with the ‘graveyard’ slot, the hour after lunch, during which time Ian was inclined to nod off. I have delightful video footage of Ian sitting in his little chair, his eyelids getting heavier and heavier, his shoulders drooping, his head beginning to drop, and Anita becoming more and more shrill, saying, “Come on, Ian! Wake up! Wake up!” waving his arms around and tickling him. Sometimes he was roused. Sometimes not and work had to be abandoned. Poor Anita. How hard she worked! She soldiered on with great fortitude despite everything, and earned all our respect.

Then we were lucky enough to find Kirsty. Our first therapists were new to the idea of an intensive home programme, but Kirsty had worked with autistic children in the United Kingdom and South Africa and was experienced in setting up home programmes for other families locally. She had taught at a Special Needs School in Cape Town, and seemed more than qualified to help us with Ian.

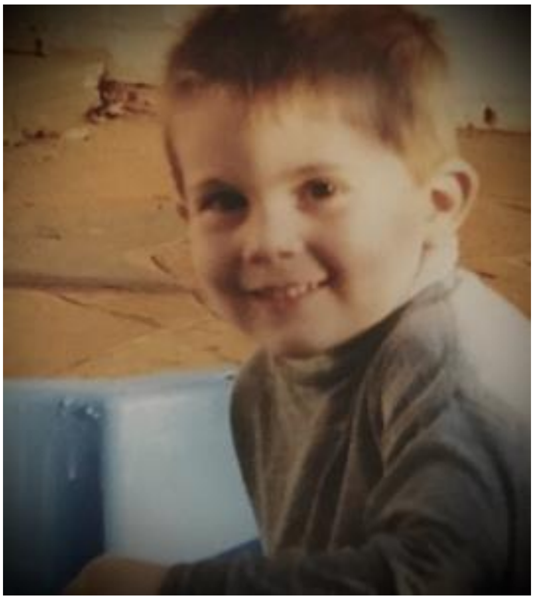
With fine white-blonde hair, intense blue eyes, lovely soft features, a gorgeous smile and wonderful patience, Kirsty quickly became Ian’s favourite tutor. Three times a week she sang to him, made him copy her movements as he learned Brain Gym, recited verses to him, showed him pictures, taught him to draw, and lit small candles and tried to get Ian to blow them out for her. How he tried! He would have tried anything for Kirsty. As the months passed and Ian progressed, Kirsty’s delightful husky voice could be heard cheering him on and singing his praises through the closed door of the classroom.

The beautiful Kirsty

She was the tutor Ian hugged most, and I think he quite simply adored her. Even when he was acting up and she would give him her stern look and say, “Come on, Ian. Try again.” He adored her even then.

* * *

Chapter Seven



Before they started working with Ian, I asked each of the tutors to read the Catherine Maurice book that both Neil and I had read. Once they had done this, they understood our motivation and were happy to accept that we believed our child's behaviour could be changed.

Ian's weekdays were divided into blocks, and the hours shared out between the tutors. Having read that the ultimate aim of an intense therapy programme was to give the child as little time as possible during the day in which to be autistic, so that behaving in a non-autistic manner would become his life-habit, we set about arranging as full a timetable as we could manage. With a constant stream of people supervising Ian's behaviour, his autistic mannerisms – his hand flapping, shrieking, hitting out and throwing objects, and his complete withdrawal from the world should – *should* – be reduced, maybe even phased out altogether.

The tiny glimpses we had had of the Ian within the autistic everyday Ian were so special, how could we not long to have this beautiful clear-eyed angel with us all the time?

With this goal in mind, we organised virtually every second of Ian's day and the dedication of the tutors in helping us to achieve this was extraordinary.

Ruth committed herself to spending two hours with Ian every weekday between the hours of 11am and 1pm. Both Tania and Anita spent an hour with Ian every weekday at different times, and Kirsty spent two hours with him, three times a week, Monday, Tuesday and Thursday. I spent time with Ian during the week padding out the hours, and over the weekends as well, to keep the momentum going. Between us, we managed to keep him busy for up to 30 hours per week and our timetable, at its best, looked something like this :

Monday	Tuesday	Wednesday	Thursday	Friday
9.00 Fiona	9.00 Fiona	9.00 Tania	9.00 Kirsty	9.00 Tania
10.00 Anita	10.00 Tania	10.00 Anita	10.00 Kirsty	10.00 Fiona
11.00 Ruth	11.00 Ruth	11.00 Ruth	11.00 Ruth	11.00 Ruth
12.00 Ruth	12.00 Ruth	12.00 Ruth	12.00 Ruth	12.00 Ruth
1.00 – 2.00 Lunch	1.00 – 2.00 Lunch	1.00 – 2.00 Lunch	1.00 – 2.00 Lunch	1.00 – 2.00 Lunch
2.00 Kirsty	2.00 Anita	2.00 Tania	2.00 Anita	2.00 Anita
3.00 Kirsty	3.00 Kirsty	3.00 Fiona	3.00 Tania	3.00 Fiona
4.00 Tania	4.00 Kirsty		4.00 – 4.30 Tania	

Keeping Ian busy didn’t just mean keeping him occupied, it meant making him concentrate, hour after hour after hour. He wasn’t going to improve because we asked him nicely. He was going to improve because we insisted. Of course, we made our insistence as pleasant as possible; we rewarded him continuously with toys he wanted, a variety of small snacks, sips of his favourite juice, big hugs and happy smiles, but we insisted nonetheless. And we insisted hour upon hour. Nothing he could do would make us go away; we were there in his face constantly with our sweet smiles and our endless requests.

My instructions to the therapists were simple: Any behaviour that didn’t conform to neurotypical development was to be addressed. This included the hand-flapping and the face pulling. Cute when he’s three, I said, not so cute when he’s thirteen, and definitely not cute when he’s twenty-three. Let’s deal with this now!

I put up a large poster in the therapy room (which I had made myself) which read "What has Ian *learned* today?" My goal was that he should learn something – anything – each and every day.

Ruth's mandate was pretty straightforward: Persuade Ian to talk. Not so much speech therapy as speech pathology – it required that she get something from nothing.

The enormity of her task was daunting, but Ruth wasn't the timid type. She began by asking Ian to say "Mmmmm" for something he wanted – on the basis that this was the simplest possible sound he could be asked to make. Ian was stubborn, but Ruth was stubborner! It didn't take him long to learn that Ruth wasn't going to go away, nor was she going to get out of his face, so if he wanted his juice, he might just as well say "Mmmm". He did, but he took his time doing it! I have hours of video footage of Ruth in those early days, kneeling on the classroom floor in front of Ian, watching him, encouraging him, and waiting for many long quiet minutes for him to respond appropriately. Ruth's persistence was extraordinary and her patience quite unbelievable.

Of course, I watched like a hawk for signs of stress – we all did – but once Ian was settled into the routine, he walked into his classroom quite happily, and calmly endured this endless tutoring.

Day after day, week after week, month after month, our lives revolved around Ian's therapy programme.

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Of course, all therapists had their own ideas – as did I – and these ideas had to be aired and examined, and a plan of action agreed upon. To this end, we tried to get together once a month to have a Therapists' Meeting. This would be held in the evening in the lounge of our house, wonderfully hosted by my husband who poured the wine.

Suddenly Ian would be faced with not one but ALL of his tutors together at the same time, and his face was always a study in horror!

In the early days when Ian was learning to make noises on request, and because we had followed Ruth's instruction that in order to teach Ian the reason for communication we had to immediately imitate any noise he made – in the hope that if we imitated him, he would learn to imitate us – we had all become used to imitating his every sound. In class, Ian would make a noise and we would echo it, and it had very quickly become second nature.

Suddenly, when we were all together, Ian – having cooed or whooped or wailed – was immediately echoed by five female voices all unconsciously producing a perfect reproduction of his coo or whoop or wail.

It had Neil in hysterics. Quite understandably, Ian fled.

With the wine flowing, and freed from the stresses of the day, these meetings quickly became relaxed and raucous. However, sometimes they also became quite heated as differing approaches and personal opinions were held on to. I recall a fairly lengthy argument one evening between Tania and Ruth. Tania wanted to teach Ian sign language to give him a means of communicating before he learned to speak. Ruth was determined to stick to her quest for direct speech from Ian. Both women were adamant their approach was the best one, and neither would back down.

Neil, ever the gentle mediator, brought the meeting to order. "We will do both," he said, "and see which method Ian favours, and which method works best for him."

Of course this made those on opposite sides work even harder to prove that their method was the best, and Ian could only benefit from this added determination!

So Ian did learn some signs. He learned that 'Mummy' was his right hand on his heart. He learned that 'finished' was the sweeping together of both palms. He learned that 'hello' was a touch to the forehead and an open hand in the air. He learned that 'same' was both forefingers tapped together side-on, hands out, palms down.

One Saturday afternoon, about three months into Ian's therapy programme, I was working in the garden, watching Ian out of the corner of my eye as he played on a ladder. I saw him looking directly at me, so I stood up straight and smiled at him.

He smiled back. Then, without hesitation, he touched his fingertips to his forehead and put his hand on his heart.   I gasped. Ian had just signed “Hello, Mummy.”

I was so moved that for a moment I couldn’t speak. With tears starting in my eyes, I walked up to him and gathered him off the ladder into the biggest hug.

“Hello, my boy. And thank you, thank you, thank you.”

That was the first time in his life that my son spoke to me.

However, Ian’s few signs didn’t have time to become really fixed before the patient hours of work paid off and Ian began to talk. Within a few short months, he was greeting his father with “Ha-o” for hello, saying “oo” for juice, “ween” for green, “nah” for no, “dzum” for jump, “tchwi” for swing, “yeh” for yes, and, bizarrely, “mummoo” for mummy. Once he proved he could be verbal, sign language was abandoned and everyone strove to increase his vocabulary – the notes in our therapy journal from this period are filled with excited sentences like these from Ruth: “Utter shock! Ian said ‘More bounce’ for me today. Well, actually it was ‘mo punce’, but WHO CARES??!”.

With Ian’s speech came exceptional moments – moments that not only validated our therapy programme, but which also permanently marked my life.

One quiet evening I had bathed Ian and was getting him ready for sleep. He was sitting in my lap as I dressed him in his pyjamas. I wasn’t really paying attention to Ian at all. I was thinking about a family get-together we would be hosting the next day, trying to remember if I’d bought enough food. It finally dawned on me that Ian was saying “mum-mee… mum-mee… mum-mee” over and over again, very deliberately. I was so used to him calling me ‘mummoo’ that this new, correct pronunciation was quite strange. I looked down at him.

“What it is, my boy?”

He stared deep into my eyes, his own eyes for once clear and intense. “Ya – o”.

I frowned. “What?”

“Ya – o,” insisted Ian.

Then it dawned, like a great wave crashing on a rock. The hairs on the back of my neck shivered. My son was telling me he loved me! He was saying ‘Love you!’ Oh my God! Stunned to the core I looked into his beautiful golden brown eyes. They were so open it was like looking directly into his soul. I could hardly breathe.

Then Ian giggled and was autistic again, and the moment was past.

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It was around this time, when every precious word from Ian had taken almost superhuman effort from everyone in the team, I found myself standing in a queue in a supermarket behind a woman with a small child. This little lad was about three or three-and-a-half years old, and he kept tugging on his mum’s trousers, saying “Mum, please may I have some juice? Please? Mum … Mum …” His language was so precise and so perfect, I listened in amazement. His mother ignored him completely.

Standing there in that public place, I felt a hot anger grow inside me. I wanted to grab this woman by the shoulders and shake her, “Listen to your son! *Listen!* He’s *talking* to you! Don’t you realise how special that is?” And at the same time I felt deeply sad for the child who was talking so perfectly and being ignored. Each word a natural miracle, falling easily from that child’s mouth. Each one a gift.
But one doesn’t accost strangers with one’s own problems. I closed my ears to the child’s pleading and walked away as fast as I could.

When I got home, I knelt down in front of Ian. I addressed him gently, “Hello, Ian.”

I watched his eyes flick in my direction. There was a pause and then he took a breath. “Ha-o… mummoo,” he said quietly.

Months of hard work; two precious jewels. I kissed him, and smiled at him, and thanked him for both of them.

* * *

There is nothing that an autistic child cannot already (physically) do, on his or her own, in the absence of any physical disability.

The challenge of a therapy programme is to get them to do it *when you ask for it.* And then to do it more than once.

Chapter Eight

With the help and dedication of this incredible team, we managed to keep our programme going for two years before our neighbourhood changed and we decided to move house.

The school Rory was attending was quite far away, and the journey there and back again, morning and afternoon, was putting a lot of strain on me. New neighbours and several loud all-night parties convinced us that our lovely quiet neighbourhood was a thing of the past, and we didn't really want to live there any longer.

Then our next-door neighbour asked his gardener to cut back the huge bougainvillea hedge between our properties and, unsupervised, the man cut a vast hole right through the centre. I was livid. Not only was our security compromised with a clear view down their driveway to the street, but Ian now had a perfect bolthole to get through when he next wanted to go walkabout. I pointedly patched the hole with a large ugly cardboard box, and that night I told Neil we were moving house. Tomorrow!

We were lucky enough to find a perfect house in Kloof, halfway between the old house and Rory's school, and still conveniently placed for Neil to get to work. We moved in during May 2000, and were extremely happy there. We had a large garden, a swimming pool and a spacious house, all fully enclosed and safe.

However, Ruth took one look around our new home, and said, "You do realise that you now have the perfect environment for Ian to be autistic."

I didn't understand what she meant at the time, but afterwards I wandered around the house and grounds and realised that she was right. Ian had as much space as he wanted to get away from us, to do his own thing. A child that safe could be supervised less, and therefore be as autistic as he wanted more often – which was exactly the opposite of what we had been trying to achieve.

After the move, the team slowly began to fall apart. The journey was a lot for the therapists and although we could still pay them for their sessions with Ian and contribute towards their petrol, we couldn't pay them for their time on the road.

Kirsty was working with several different families and the pressures on her were immense. She needed to take a complete break for several months, and after that would only be available to us for consulting and assessing. This was a huge loss to us. Kirsty was an integral part of our team as well as being Ian's favourite tutor. We all listened to her opinion when it came to Ian's education. For myself particularly, Kirsty had become a close friend, and I knew I was going to miss her.

Then Ruth pulled out. She was finishing her doctorate and was under enormous pressure – particularly as the university, which had initially supported her doctoral thesis, was now threatening to withdraw its support. Ruth's thesis was perhaps more contentious than they had originally thought, and their ongoing refusal to recognise her work turned Ruth into a nervous wreck.

Tania said she had to concentrate on her city practice and she stopped coming.

The final blow came when Anita got married, and her husband did not want her to continue working.

Our team had disintegrated within six months of our move and we found ourselves stranded.

Ian had progressed so much. By that stage, he had learned to write and draw; he was typing on the computer; and, thanks to Ruth, he had learned to answer questions properly, and could ask for anything he needed. He could say “Please,” “Thank you,” and “Excuse me” as necessary and was, to my mind, as near ‘normal’ as it was possible for him to be.

I passed him in the lounge one morning and said, “Hi Ian” as I walked by, and he immediately responded “Hi Mummy”, with a big smile on his face, making appropriate, uncoerced eye contact.

It really was a Wow! moment. We had achieved much of the change we wanted.

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With no alternative on the horizon, I enrolled Ian in the pre-kindergarten group at the school Rory was attending. It catered for two-and-a-half to four-year-olds and although Ian was now a strapping great six, Barbara, the generous, gentle woman in charge, was happy to take him in.

Mixing Ian with a small group of typical kids was a huge success. It took him a while to adjust, and I had to go through a rather awful patch of separation anxiety where Ian cried and cried when I left him in the mornings, but this in itself was so gorgeously *normal* it had implications for me I knew no one else would really understand.

The other, smaller, children accepted Ian with love and generosity. He was a gentle giant among them, towering over even the tallest child in the class, and when he took their toys from them, they took them right back with frowns and complaints, and Ian learned the give and take of normal play.

Every morning they had circle time, and because Ian seemed not to want to hold hands with the other children, he was allowed to stand in the centre of the circle as they sang their morning songs. Barbara told me how Ian would turn around slowly with a little smile on his face while the children were singing, as if he wanted to watch each child, and then, when they stopped, he would take over and sing their whole song back to them. This delighted the children and they always cheered and applauded after Ian had finished.

The only problem with mixing an older child in this group reared its unexpected head one day during playtime. Ian, bigger, stronger and autistically unafraid, climbed the tree in the playground, right to the very top. I arrived to fetch him just at that moment, when Barbara was wondering what on earth to do next. I could see at a glance what her problem was – she didn’t want to leave the little ones unattended on the ground while she retrieved Ian, nor did she want to climb the tree herself, which might encourage the smaller children to follow her. So, ignoring the rather lovely white dress I happened to be wearing, I shinned up the tree to collect my son.

Ian was so used to playing physically with me that the minute I touched his arm he let go of his branch and would have fallen straight to the ground if I hadn’t managed to grab him firmly around his wrist. I held Ian tightly with one hand while he dangled out of the tree, and, with his full weight hanging off me, I was able to lean sideways and lower him to Barbara, who supported him the few remaining feet to the ground. Thank heavens all that swinging and tossing that Ian enjoyed so much had developed the muscles in my arms and shoulders!

Obviously Ian was not presenting the best example to his classmates, and after this incident I had to make sure that I arrived in time to fetch him before break time started. Barbara really didn’t want other smaller children climbing beyond her reach.

But watching Ian blossom during these few months, I realised that mixing an autistic child with typical kids of a younger age represented the very best that could be achieved. It had done Ian the world of good and he had learned to behave appropriately with the group in a way he never would have, mixing with other autistic children or at home in an intensive home programme.

However, I still wanted Ian to be involved in some intense classroom-type learning, so in addition to mornings at the Roseway pre-Kindergarten (delightfully named Little Rosebuds), I enlisted the help of some retired teachers who lived in our neighbourhood.

These three women, I hoped, would have the teaching experience to keep Ian busy given that he was, at that stage, learning in a more normal way. However, it quickly became clear that they were all unsure how to approach Ian, and – clever little blighter that he was – he took great delight in running rings around them, day after day. These kind women just shook their heads. They really had no idea how to deal effectively with him. The most determined of them did get some results, but mostly they ended up working a great deal harder than Ian.

However, all of this fell apart when we made the biggest decision of our lives.

* * *

The photograph of Ian (above) is my most favourite photo of him, ever. It shows him at Little Rosebuds, interacting with two of his friends there. This in itself is glorious – the autistic child, *interacting*.

Chapter Nine

Taken on the plane, during those few precious hours when Ian was asleep.
Rory is drawing, and Neil is in the background, stretching his legs.

We were finding life in South Africa a great strain. Both Neil and I worried constantly about the other's safety, and together we worried about our children's safety and also about their future. Many months of accumulated stress combined one day to force me to say out loud what I had for a long time been thinking: "I don't want to live in this country any longer", and to my great surprise Neil answered immediately, "Neither do I".

But where to go?

Obviously an English-speaking country was a prerequisite, but neither of us was keen on the usual choices – Australia and New Zealand, America and Canada, or the UK. English by birth, I knew that after so many years away from England I was no longer truly English and wouldn't fit in as easily as many South Africans might have thought. In South Africa, I was obviously English; in England, perhaps less so.

When Neil suggested Ireland I was very surprised, but pleased too. Living in Durban, I had grown accustomed to an exotic, subtropical land, surrounded by strange and colourful wildlife and strange, colourful and lush plants. I sensed that Ireland, with its aura of romance and mystique, could provide, if not an equally strange and exotic life, then a comparably colourful one. The more we thought about it, the more attractive the idea became.

Neil visited Ireland for two weeks during 2001, attending interviews and having a look around a country neither of us had visited before. He returned home raving about the place! He also came brandishing pamphlets, which he had picked up along the way, which set out the services available to an autistic child in Ireland.

We devoured these with great interest, reading with growing excitement about the number of State schools which had units specifically set up for autistic children. These promised one teacher and two helpers to every six children, and there appeared to be up to four of these schools in each area. In South Africa in the 1990s, we had been left to make our way entirely on our own, created by us and paid for by us. We had never imagined there could be such a variety of help anywhere in the world! Our imaginations fired up and our appetites whetted, we couldn’t wait to get there.

Lock, stock and barrel, we sold up and moved. My enthusiasm for this new venture was dampened only by having to leave behind my precious Border Collies, Meg, Queenie and Skye.

The flight to London was long, and Ian slept for only a few hours of it. Then, wide awake in the small hours, when most people had finally succumbed to an exhausted doze, he needed constant entertainment to keep him quiet. Not many would make allowance for a noisy child at two o’clock in the morning, special needs or no.

Somehow I managed to keep him busy, going through our entire repertoire of table work, getting Ian to read, write, identify, clarify, draw and colour in – most of which he did incredibly quietly, but it meant that I had to be at the peak of my persuasive powers to keep him focused. Not easy at two, three, four and five o’clock in the morning. When we arrived at Heathrow, I was utterly shattered.

Our landing at the airport was dreadful – we hit the runway with incredible force and I swear the plane bounced at least twice. Could this journey get any worse, I thought? Yes, apparently it could. Ian promptly vomited all down his front.

I had no change of clothes for him and everything he was wearing was now quite disgusting. Who carries a spare set of clothes for a six-year-old? Nothing for it but to strip him completely and dress him in my brightly-coloured, fair-isle cardigan, which reached his ankles and, buttons done up from top to bottom, made him look like a little refugee from Peru.

It's tough enough hanging around in an airport with a tired special needs child. Hanging around with a tired special needs child dressed in an eye-catchingly outrageous fashion takes a very thick skin.

That day I found I had one.

* * *

What I hadn't included in this story originally was that while we were at Heathrow Airport (in the UK), Neil disappeared. Rory, Ian and I had sailed through customs on our British passports, leaving Neil to go looking for a t-shirt to buy for Ian.

We waited for him downstairs, but he never appeared.

I walked the entire terminal – with both children by my side, Ian still in my brightly-coloured cardigan – trying to find Neil. Backwards and forwards, backwards and forwards. There was no sign of him anywhere.

Hours later, with the time to board our flight to Ireland fast approaching, Neil reappeared, looking pale and shaken. The bastards at Customs had detained him and some officious little prick had grilled him for two hours, refusing to explain why he was being held, refusing to let me know that Neil was in custody, and refusing to make a single telephone call to verify the facts Neil was telling him.

It was an extremely unhappy experience for us all, and we couldn't wait to catch our connecting flight out of the UK, and into Ireland.

Chapter Ten

As soon as we were settled into our new home in this beautiful new country, I started collecting telephone numbers of people who may be able to help us with Ian.

My first port of call was the nearest school, which had an Autism Unit. I telephoned the headmistress there and, with some reluctance, she agreed to meet with me.

Filled with naïve optimism, I made my way to meet the headmistress of the school and the teacher in charge of the Autism Unit. This was one of the reasons we had come to Ireland, the opportunity for appropriate schooling for our son.

They were not pleased to see me. Their unfriendly faces were matched by tacit hostility towards me as I described the home programme we had in place for Ian in South Africa.

Despite the fact that the unit was supposed to cater for six children, the headmistress kept saying it was full, even though I knew that there were only four children attending. Still, both she and the special needs teacher told me more than once that there wasn't room for my child.

I was puzzled and slightly shocked. I had expected them to be interested in Ian's progress, to want to know about Ian and what he'd learned. Instead I found that they were *uninterested* in what we might have done and *completely unimpressed* by what Ian might have learned.

I somehow kept the smile on my face but left as soon as I could, pretty certain in my own mind that it was not the place I wanted for Ian. *

However, other than that school – and other schools like it, but much further away – there was nothing else. I made phone call after phone call, pleading in vain with people who should have been in a position to help me, but couldn't. What I wanted for my child just didn't exist. **

I ended my last call deeply depressed. I was no further forward than I had been when I started. Here I was, in a new country, knowing virtually no one, desperately needing help, and feeling very much alone.

On paper, Ireland was Nirvana for the autistic child. It soon became apparent that these smart pamphlets were almost works of fiction.

There was nothing else for it. In the absence of something which I believed to be suitable for my son, I would have to continue Ian's education at home, by myself.

So that's what I did.

I gathered together some of Ian's books from his bedroom, an assortment of toys, plastic letters, pens and paper, and sat down with him in the lounge at the coffee table. I seated Ian on the footstool, and I sat on the couch or on the floor beside him.

I knew which words Ian could read, and so I made a 'book' for him combining words he knew with new words he could learn, drawing pictures and writing neatly on plain A4 paper and stapling the lot together. I placed the book in front of him and read the words on the first page to him. Then I pointed to the first word and waited for Ian to read it back to me. He did. I pointed to the second word, which I knew he could read too. I waited. He read. I knew Ian didn't know the third word, but I pointed to it anyway and waited. Ian glanced up at me, so I read the word for him and asked him to repeat it. My finger was still pointing to the word, and it stayed there until Ian read it to me. Then we read those first three words again, and this time Ian didn't hesitate on the third word. Yes! He had just learned something new. I turned the page and we carried on.

We worked like this every morning. Within a week, I could set aside my homemade book as Ian could now read it from end to end. We moved on to others.

With my help, Ian learned to read all his books, to write sentences, do bigger and more complicated puzzles, and spell the names of his favourite animals with his plastic letters. He seemed more than happy to work at home, and appeared content with me as his only teacher.

His reading improved in leaps and bounds, his vocabulary was increasing almost daily and, once his work ethic was firmly re-established, he sat at the coffee table hour after hour, day after day, quite content.

This could not be forever, though. I just couldn't see myself teaching Ian in perpetuity. So when two children left the Autism Unit at the school I had visited, and a place was offered to Ian, I rather reluctantly agreed to give it a go.

* * *

* If I was looking for enthusiasm, good energy, fun, and an upbeat learning environment, this Autism Unit was most definitely not it.

** In a perfect world, I had hoped to get Ian into a set up similar to the one we enjoyed in SA – into a group of younger children where he could benefit from acceptance without judgment, but where he would be guided by neuro-typical kids into a more 'normal' way of being. Young children are generally pretty accepting of another child's oddities, before they acquire their own (adult-influenced) moral radar. But such a thing was unheard of in Ireland. I couldn't even get Ian into a primary school class with (my) full supervision, on the premise that it would 'distract the other children'.

Chapter Eleven

What struck me first and most strongly was the fact that neither the teacher nor the Special Needs Assistants expressed any interest in what Ian already knew. I couldn't understand this. Why didn't they ask me? I had told them he had been in an intensive home programme for several years but not once did anyone ask me what he had already learned.

To be honest, at the time I found this quite sinister. In retrospect, their arrogance was stunning. In their minds, I was just the mother. I couldn't possibly understand the things they knew. After all, they had all been on Special Courses. They held Degrees! They were Masters of their own Universe! *

I tried to be kind. They appeared, on the face of it, to be good people trying to do the best job they could, and yet … Surely, no teacher in the world accepts a new pupil without at least some idea of what that pupil already knows? Why should it be any different just because he has special needs?

I got the strongest feeling that they felt threatened by me and they seemed to be deeply secretive and protective of their teaching programme and their teaching methods. **

I told myself I was being over-sensitive, however, and decided to give them a chance. In the meantime I would watch and wait.

* * *

When Ian finally started school, the teacher I had met at my interview with the headmistress was away on leave and would remain so for many months to come. In her place was a new lass; a friendlier young woman who had some experience teaching typical kids but was new to the idea of teaching autistic children. She appeared to want to listen to me and took to heart some of what I told her about Ian. As she would be in charge of Ian's schooling, I spent a lot of time encouraging and nurturing this wonderful person, this beacon of light in otherwise murky waters.

It was thanks to her that Ian settled in well and seemed to be enjoying himself. Because he was happy, I convinced myself to back off and give him space.

Around this time I wrote to Ian's erstwhile tutors in South Africa –

"Ian's teacher and I keep in constant contact either through notes or discussion, about the things he's done or not done, and how best to work at them. He's still not being pushed adequately at school (in my opinion), and far too much allowance is made for his autistic mannerisms, which means that instead of receding, they continue in full force.

Ian is doing well enough at the unit, seeming to still enjoy it, learning as little as they will let him get away with. He gets away with a lot, with the result that he learns little!

His teacher is doing what she can but she often seems puzzled by Ian's changeability from one week to the next, his constantly altering behaviours and his one-step-forward-two-steps-back approach to life. I'm encouraging her as much as I can, and help Ian with his 'homework' on a daily basis which keeps me in touch with what he's supposedly learning, and gives me an opportunity to push him in a one-on-one session at home before his brother gets home from school and we settle down to Rory's slightly more taxing homework.

One of the things Ian's getting better at is colouring in – at least he seems to understand that the colour should stay inside the lines, but the downside of this is that he's tending to use his pen in short straight strokes, which doesn't help him *when it comes to writing. In steps Mum, who makes him scribble in wild circles, which seems to improve his confidence and strengthen his pen-holding technique.*

At school his teacher makes him join the dots to form a page of the letter 'C'. At home I make him write the whole alphabet free-hand …"

However, as the months passed, Ian's behaviour began to deteriorate almost by the week. He had been thoroughly enjoying the freedom offered at the unit, but his clever mind was now bored, and this began to show in his behaviour.

In the early days of our intensive therapy programme we had found that no sooner had one nasty mannerism been brought under control than another would rear its ugly head. We fought our way through them, one by one, until Ian reached a stage when he didn't seem to need them anymore. This was the time when I felt he was 'as near normal as it was possible for him to be', because without his autistic hand flapping, face pulling, finger twitching or posturing, he behaved like any other kid.

Now, in the absence of any intellectual challenge, any check on his autistic behaviours, and thoroughly bored at school, these mannerisms were all re-surfacing. Not one by one, but *together*.

But I was desperately trying to fit in to this new country, trying to accept a new way of doing things and, anxious and more than a little depressed, I started second-guessing myself. I had been patted on the head with 'there, there, she's just his mother' once too often, and got to the stage where I almost believed it. I began to question whether I really knew what was best for my child. However, in the absence of any real, concrete help in which I could believe, it was easier to back off and let the professionals get on with it.

The downside of this, of course, was that Ian's behaviour continued to deteriorate. All his oddities returned in full force, all the mannerisms, all the self-chatter, the weird facial expressions.

It seemed that at the school they regarded ANY response from Ian as a good sign, with the result that they ended up re-enforcing the wrong behaviour constantly. By way of example, I learned that he had spent a good deal of time one afternoon singing with one of the Junior Infants (they integrated once a week), repeating a phrase from one of his favourite videos – the song Everybody Wants To Be A Cat from the AristoCats. Over and over, the same lines. And when the little girl stopped singing, Ian would take her arm and sing the line to her, thereby initiating more repetition of the same thing.

Ian was brazenly self-stimming – indulging in the most wanton, unnecessary autistic behaviour, which we (the therapy team in South Africa) had taken *months* to diminish – and this was regarded as a coup of some sort, a 'meaningful sharing of time'. I wanted to weep!

They worked on his reading, his writing and 'maths' (merely counting 'how many?') without concern (understanding?) for the lack of foundation for the work they did. They followed the curriculum set out for "Learning Disabled Children" (that's disabilities across the board) and were happy that Ian could accurately trace a whole page of the number '1', and read to page sixteen in his set workbook, even though he didn't comprehend a *single word* of what he was reading about.

Nothing was *real*, nothing had meaning for Ian in the greater scheme of things. Everything we had worked so hard to achieve was evaporating, disappearing like smoke on a windy day.

And why didn't I say something? How could I, of all people, NOT say something?

I gnawed on this issue for days, knowing full well that there was no way for me to change the minds of people so set in their ways without precipitating a major confrontation, which – as long as Ian was still at school – I really didn't want. And with the headmistress taking the 'if you don't like it, remove your child' stance, it was a difficult position to be in. ***

However, when Ian came home at the end of the year with a crushingly disheartening school report – merely a list of the things the teachers had managed to get out of him, a testimony to their 'success' rather than a record of what Ian might have learned – I knew I had to make something happen. Ian's behaviour had regressed even further, and I was genuinely concerned. ****

I tried to convince myself that these were good people doing their best, but what worried me more than anything was the precious months which had been *wasted* while these teachers stumbled around ‘teaching’ my son things he had already left far behind. And teaching them so badly that he had unlearned large chunks of what he already knew.

Something had to change.

* * *

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* It wasn’t that they ignored what I might know, it was that they *assumed I knew nothing.* This was the first time in my life I had met people who saw my son not as a human being but as a diagnosis. He wasn’t Ian, he was Autism, and Autism was what they believed they knew. I wished the people ‘in charge’ would accept that every parent of an autistic child has read more about autism and researched more about autism than they ever will, plus they have lived with autism 24/7 sometimes for years before they even get near any help.

** Whenever I asked what they would be working on with Ian, the subject was avoided or I was just plain blanked.

*** Yes, she really did say those words to me.

**** This file was filled with pages and pages of the same three exercises, completed in the same way and *with the same level of success* every single day over several months. The same tasks again and again, with no progression and absolutely no challenge to Ian. I was simultaneously furiously angry and utterly depressed. I couldn’t understand how these people could not see the potential which literally shone out of my son’s eyes.

Chapter Twelve

It was during these summer holidays that Ian attended a course of Auditory Integration Therapy, which aims to address the sensory problems such as hearing distortion and hyperacusis (oversensitive hearing). These are said to cause discomfort and confusion in people suffering from learning disabilities, including Autism. The hypersensitivities are believed to interfere with a child's attention, comprehension, and ability to learn. "AIT is designed to improve the person's ability to process sounds by 're-educating' the brain. This is done by playing electronically modified music or other sounds in which the frequencies have been changed".

At first Ian seemed a little stunned by the sounds coming into his ears through the headphones. It certainly wasn't music he would ever have heard before, and after being messed about with by the machine even less so, although he did seem happier when the New Orleans jazz track came on! However, he remained mostly silent throughout, at times almost stunned and he just sat, staring into space without moving.

Towards the end of the first week he became quite noisy, almost experimenting with his inability to hear his own voice because of the earphones. Because Ian couldn't hear me, there was no point my trying to tell him to be quiet, so I wrote down on a piece of paper "Stop" and "Mouth Quiet", pointing to my eyes with two fingers for ‘Look at me’, pointing to the paper for him to read the words, and then giving him a thumbs up for ‘Good’ when he quietened down again.

The speech therapist was astonished by this silent exchange of information, all of which had the desired effect, and in my head I found myself thinking *Yes, my son can read, and yes, he does understand.* Again, I was dismayed by the lack of understanding of the autistic mind, and the inability to see the working mind behind the eyes. “Push a bit”, I wanted to say, “You may be astonished by the results”.

For the first week, the AIT seemed to be working some kind of magic. I noticed that Ian was forming longer sentences than usual – instead of saying his usual “Juice please, Mummy” he was now saying “Ian want juice please, Mummy,” and he responded quickly and without complaint to requests which previously may have been met with some form of resistance.

However, the second week of AIT seemed to take him back to square one. In fact, he appeared to be experimenting with his autism, almost milking it for what it was worth, and there was a definite resurgence in certain iffy behaviours. I certainly didn’t appreciate the deliberate elbow into my throat, which Ian managed to deliver when I was brushing his teeth one morning. *Ouch!*

Ian continued to accept the headphones and sounds because he’s amenable that way, although he was keen for it to be over and he said quite clearly more than once, “Ian want ‘working is finished’ please Mummy”* – possibly his longest spontaneous unsolicited sentence yet. However, generally I felt that whatever had been achieved in that first week had been undone by the second.

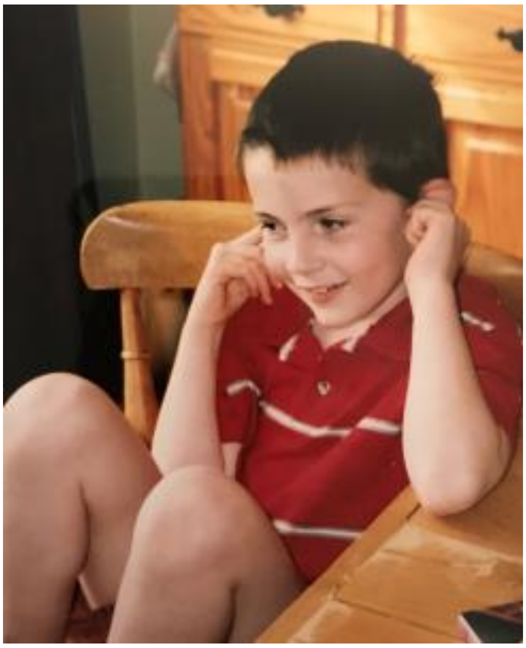
Once Auditory Integration was over, our sessions returned to normal speech therapy.

During one of these sessions, the speech therapist had shown Ian an illustration of an animal with the query, “What is this?” – to which I somehow fully expected Ian to reply “*Well, it’s a cardboard square bearing an infantile representation of a tiger, otherwise known as a flashcard or picture*”. This rather mad thought ran through my head because I lived in a world of endless possibility with Ian, where what he actually did and what I *believed he could do* may not always coincide, but where the chance of them coinciding could never be ignored.

In truth, I believed that Ian stored his extensive knowledge in a clearly compartment-talised filing system, and the identification of any animal would be found in his brain in the general file “Animal”, and the information required could be retrieved accurately and swiftly by posing the alternate question “What animal?” Cautious to step forward and demonstrate, I showed the speech therapist that Ian would respond almost immediately to a question phrased this way, when he was taking up to twenty seconds to give an answer to her question ‘What is this?’

Then she presented him with an alphabet of plastic letters and he promptly set about lining up the letters to make the names of the various animals on the flashcards, one after the other : tiger, elephant, bird, lion, Cinderella … *No, Ian! Focus!*

Importantly, during the holidays a spark returned to Ian’s eyes which I hadn’t seen for a long time. There was a clarity in his sustained eye-contact, and I suddenly found myself loathe to send him back to the Autism Unit where I knew they would not only not notice the spark, they would extinguish it.



* * *

* The phrase ‘working is finished’ came from the early days when we were teaching Ian sign language. At the end of each therapy session, the therapist would say “Working is *finished*!” giving Ian the hand sign for ‘finished’ as they said it. Ian latched onto this, and never forgot.

Chapter Thirteen

Time was marching on, the holidays were passing, and I had to make a decision. Was I going to take Ian back to the Autism Unit? In all honesty I just couldn't face it.

I agonised and soul-searched and weighed up all the pros and cons over many sleepless nights, and finally made the decision to remove Ian from the school and reimplement a home-schooling programme.

I felt all weak and pathetic for a while, but then I found myself again and knew that I had made the right decision. So I telephoned the Schools Inspector who sounded oh, so very sad when I spoke to him, but after I had stumbled through my well-rehearsed list of reasons, refused to point fingers at anyone or anything (although he kept digging for a name), and emphasised, yet again, that it wasn't a decision taken lightly, he assured me that he was available for any advice or help I might need. I could contact him at any time. Letting the headmistress of the school know took courage I didn't know I had, but she received the news surprisingly well (she'd probably already spoken to the Inspector) and, faced with my grovelling, obsequious patter, ended our conversation almost – but not quite – wishing me luck.

Suddenly we were on our own.

In effect, what I had done by removing my child from school was raising a strategic digit at the Education Department and saying "I can teach my child better than your qualified teachers" which is never a really clever thing to say, even when buoyed up by the best of intentions. It wasn't a comfortable place to be.

However, I knew that my child did not need day care. He needed to *learn*. These children are not brain damaged, they are *brain different*. Their ability to learn, their capacity to learn is there, fully formed and accessible, hiding – sometimes very effectively – behind their autistic mannerisms. These children need people who are prepared to work their way through the barrier of distracting behaviour to the Well Of Possibility within, the jam inside the autistic donut. If no one believes that Well Of Possibility exists, no one will *ever*be determined enough to make a difference. Making a difference means changing the status quo, encouraging the child to be more than the sum of his behaviours. It means not judging the child by his diagnosis or by his condition, but approaching him as a person first, an autistic person second.

I knew Ian had a working mind hidden behind a barrier of autistic behaviour, but that his capacity to learn and his *desire* to learn were unaffected by his condition. Ian didn't have a learning disability; he had a brain that provided him with too many distractors, which prevented him from learning easily. But he had proved himself hugely capable of learning and deserved the opportunity to learn more.

Of course, the little man knew none of these things. He was ambling through his life most unconcerned. I was, at this time, teaching him to lay the table for meals – and never had you seen placemats set so straight! – to lock and unlock the car for me; to carry shopping bags to the car and put them in the boot; and to bring me the things I asked for. In everything, he learned new words. I made sure that he could not only read them but understand their meaning as well. I felt that the Autism Unit's insistence that Ian read a book about animals having a party in the park (complete with drag racing) by pure word recognition, without understanding any of it, made me all the more determined that he should have an education that actually meant something to him. Comprehension, rather than party tricks.

I also found that, thanks to his months in the Autism Unit, Ian had been so *over-helped* that he had lost his ability to start counting by himself. So when I said "Okay, Ian, let's count", he would sit looking at me, waiting for me to start. There was no way I was going to do it for him, to say "One…" so I sat and looked back at him, and waited.
"Count, Ian", I reminded him gently. And waited. Many long minutes went by, and he needed reminding several times, but he eventually got the message and tentatively started, "One, two, three……". "Good counting, Ian! Let's do that again. Ian, count for me", and he sat looking at me, waiting for me to start. So I waited again. It took weeks to get him beyond this block, but we did get beyond it in the end.

About to embark on schooling my son by myself again, I wrote to Ian's erstwhile tutor, Kirsty, who had become a close friend. We had kept in touch and she was always very interested in Ian's progress. Her support kept me going through some difficult, soul-searching times. She wrote back to me –

"…it was great to read your feedback. But reading it really gave me an overwhelming feeling of what a wonderful mother you are for Ian, and how far he has come, and continues to progress. Just reading about his responses and his language and other abilities is still truly exciting for me. You have never just "let him be" and your expectation for him to participate in our world is inspirational. I know because of who you are that you would think "But what other way is there?" but believe me so few parents ever grasp the concept, even after years.

Such small things like setting the table make such a difference, and I laughed out loud at the perfection of the place settings, knowing that dear man-boy as I do! I really hope I can get to meet him again one day.

That is great, that you're going for the home schooling option again. I am sure you have made the right decision, for your instincts about systems, people and your children are acute and always intact, and one cannot forget that Ian has come as *far as he has thanks to those instincts of yours. Of course you can make it happen; you have done it before, and you know the right path for Ian."*

Who could not be buoyed up when supported by friends such as her? Even with six thousand miles between us, our friendship remained strong and I asked her opinion and advice on virtually every aspect of Ian's schooling.

I drew up a rough therapy schedule of things I felt Ian could do or perhaps should learn to do, gathered together some equipment (books, pens, paper, table and chairs, and the like), and home-schooling commenced.

The order of events was likely to change on a whim, but the schedule looked something like this –

Meet-and-greet – with appropriate eye contact and social responses

Days of the week – changing the arrow on the chart

Weather

Brain gym

Reading – any book that can be 'made real' ("Spot looks out the window" – Ian, point to the window. Good, go and look out the window. Come back and sit.)

Gross motor trials (more of a gym session really, touching toes, balancing on one foot, lifting chairs, jumping, swinging arms, etc. Very physical)

Vocal skills – object identification in more than one word answers (Q: What is this? A: It's a pen!)

Prepositions – on/under, in/out, in front/behind, next to, over, through, etc

Time out – swinging on the swing, running around the garden

Songs / clapping / drumming / then sitting quietly, hands down

Fine motor trials (thumbs up, wiggle fingers, tapping index finger and thumb, tapping index finger with hands flat on the table)

Drawing and writing (painting too, in due course)

Maths – how many? and basic 1+1= (I lived in hope!)

Reading – building confidence and learning new words

I found I could easily fill two to three hours with this routine, by which time both of us needed a break. Ian's work ethic had gone out the window since our days of a rigorous therapy timetable, so that had to be addressed immediately; but the thing I noticed first and foremost was how much he had grown up since I had worked with him last. Suddenly I was faced, not with a toddler, but with a strapping, nearly-eight-year-old lad who was as stubborn as a mule and could turn on the "I'm seriously autistic" mode in a flash, and entirely at will.

Oh boy! We sat in silence as the minutes ticked by, Ian staring into space and refusing to read the word 'The', me digging in my own heels and refusing to prompt him. Eventually I begged him, in several desperate grown-up sentences, to read the words for me before I had a nervous breakdown. So he read the whole sentence fluently and without stopping. And then he refused to read anything else.

And thus it went. In some ways, it was a difficult match. My expectations were high; I knew what Ian used to be able to do and I knew what *I believed he ought to be able to do*. I persevered. He would not beat me in stubbornness, and he would not convince me he was more autistic than I knew him to be. Even after only a few days, there were some improvements that I could see. Little ones, but improvements nonetheless.
Around this time I wrote an update to Kirsty –

"Working through the prepositions is the only time he really, really has to think, because I put three objects on the table and say things like, "Put the cow and the Lion under the box," and he really has to listen, otherwise he gets it all wrong!

With the 'how many', I'm working with blue glass beads – they're flat on the back so they don't roll around on the table. With the beads lined up on the table in front of Ian, I can add to them or take them away as I please, and use Ian's fingers to move them away from the line and get him to count by asking "How many beads?" I hope that the tangible identical beads will help the idea sink in better than pictures in a book. I suspect that to an autistic child, a blanket "How many?" could refer to motes of dust floating in the room, as much as pages in a book or colours on the page, as opposed to what we may expect him to count, say the number of flowers illustrated on a page. Ian's very literal, as you know, and I'm trying to narrow the field by using something small and very specific. It may work. It may not. Time will tell."

Extras

I thought you might like to see a couple of snippets of video footage of Ian in class with me, shortly after we started home-schooling, so here you are. They may take a moment to load, and seem to pause half way through – but if you're patient, all should be well.

https://fromtheinsidedotorg.files.wordpress.com/2020/09/img_8546.mov

It was easy to teach Ian the names of animals, to point to them, or ask him to give them to me. I decided – in my endless quest to increase / improve Ian's language skills – to ask him to respond to the question "Which one …?" with the answer "This one!" I felt it was also important for Ian to be able to contradict me by asking him to point to something which wasn't on the table.

https://fromtheinsidedotorg.files.wordpress.com/2020/09/img_8552.mov

Ian loved opposites, and I enjoyed this exercise because it incorporated reading, matching, and required him to know his opposites as well. In fact, the only problem he had with this task was slowing down!

Chapter Fourteen

It seems autistic children can be divided into two groups – those who run away, and those who don't.

It took us several years to discover that Ian was a runner. Perhaps because we lived in South Africa, we were lucky. Our grounds were fenced and locked in any event and, apart from that awful time when the bougainvillea hedge was hacked to shreds and our security was breached, there was never a moment when Ian could have wandered off on his own. We had an inkling perhaps – he had snuck out the gate when a delivery was being made, but I noticed him doing it and called him back – but we had no real understanding of the seriousness of it.

When we first arrived in Ireland, our new home had a low front wall and a gate which was only three feet high. This didn't concern us initially. We even have a photograph of Ian sitting on the front pillar (above), that's how unconcerned we were.

Ian and his brother played outdoors constantly that first glorious Irish summer (I'm not being sarcastic, it really was warm and sunny that year!) and we didn't worry about him at all. Ian was never far off our radar; that's just the way things were. We kept an eye on him simply because of who he was.

And then one day I was gardening and I walked around the side of the house to empty my basket into the compost bin. I was out of sight for only a moment, and I fully expected to find Ian in the garden where I had left him when I returned, but he wasn't there. I walked right around the house, thinking he must have rounded a corner ahead of me. No, he hadn't. Alarm bells were beginning to ring. He wasn't in the field either. Last option: his bedroom.

No Ian.

I burst in on my husband, startling him as he was working.

"Ian's gone."

Those small words changed our entire lives.

Where we live, high on a mountainside in a deeply rural area, the roads are filled with options for the wandering child. Out the front gate, and we were faced with our first problem: Did he go right or left?

If he went right, he could have gone down the hill towards the bridge (fast-flowing river), or up, towards the mountain (a vast expanse of tracks and open space to get lost in).

If he'd turned left out the gate, there was a lane off to the right, a potential left turn (up the mountain again); two attractive forest paths where Ian was used to going for a walk; a crossroads; and, if he hadn't been stopped before he got to it, a busy National Road.

Our blood ran cold. Absolutely nothing in life prepares you for the empty road and the mind-numbing horror of a missing child. A child who has the speed, agility and determination of a seven year old but absolutely zero sense of danger? Double it, at least.

Neil and I flew in opposite directions on foot. I ran to a near neighbour begging for assistance, and without hesitation she jumped into her car and roared down the lane towards the bridge. I forced myself up the hill towards the mountain.

I learned that day that fear leaves you weak and breathless, and my run up the hill became a panicky gasping walk. If Ian was running – and there was every chance he was – he was outstripping me with every step.

This was in the days before everyone had a mobile phone, so we were all alone in our desperate search, with no way of communicating.

I heard a car behind me and I turned around, ready to ask a passing tourist if they'd seen a young lad in a blue t-shirt and shorts with bare feet running in the road … but it was my neighbour. She had found Ian a mile and a half down the lane, almost at the bridge, and still running. Her biggest concern when she'd stopped the car had been whether he would get in as he didn't know her well; and then she became even more concerned when he did.

"Would he do that for anyone?" she asked me. It was a grim truth. Yes, Ian loved travelling by car, so yes, he would get into any car, with anyone. It didn't matter whether he knew them or not.

The next day, the man came to put up the six-foot fence, and Neil built up the brick pillars and we had them measured for six-foot gates. We didn't have a padlock at first, but another 'walkabout' changed all that. This time Ian went left out the gate instead of right, but he was seen by a neighbour, running past their house, and was quickly caught.

One day Ian carried a chair to the new gate, and spent a while looking at the chair-to-gate ratio, weighing up opportunities. Another time I watched him carry the aluminium ladder to the gate and climb it, but I think the potential fall on the other side of the gate was enough to change his mind.

Autistic, not stupid.

I tried to be brave, to let him work out the impossibility of escape for himself, but it was hard to watch him trying. Did he *really* want to leave? Or was he playing some private game?

Locks became a way of life for us after that. Ian’s bedroom window remains locked so he doesn’t climb out of it; the front door is locked; and the front gate is locked *all the time.*
All because we are desperate to keep our child safe, and because we live in fear of those few little words:

“Ian’s gone.”

* * *

Many years later, as Ian was finding his way in adult services and adjusting to a new day centre – and, of course, causing ripples because of security issues – it was suggested to me that maybe Ian had ‘grown out’ of his need to run away. Maybe Ian’s desire to escape should be ‘tested’ by giving him an opportunity to do it.

I rounded on this man with all the suppressed rage of the over-tested mother, and said “I hope you can run *VERY* fast, because when my son is found dead in a ditch a hundred miles from home, I’ll be coming after *you.*”

Needless to say, it wasn’t tried.

Then Ian made his own case one day when he dodged away from his support staff on a visit to town, and gave them all the fright of their lives. He was quickly stopped, thank heavens, but the lesson was learned, once and for all.

Our lives revolve around this.

Chapter Fifteen

School with Ian swung between rewarding and occasionally frustrating but I knew he was learning things. Within one week he learned to put on his own socks (once he got beyond the idea that I would help him do it), and he could undo buttons as well as doing them up. He was counting objects on the table and giving me a confident and full response, “There are twenty-seven beads!” when I asked him how many of the blue beads there were.

It had taken a few weeks but he got there.

He learned to squat and stand on one leg by himself during our exercise session, to co-ordinate saying ‘out’ and ‘in’ with the movements in star jumps, and he could, at last, touch his toes while I held his knees*. He could cut reasonably well with a pair of scissors – when I gave him a pair sharp enough to cut. He could differentiate between and point to ‘big’ or ‘little’ objects, although occasionally he did so appallingly badly I would wonder how he’d got nine out of ten for the same exercise the previous day! His writing was improving slowly and his reading could be extraordinary, depending on the position of the stars…

On the downside, despite my best efforts, he still had no understanding of the concept of ‘weather’ – or maybe he really did, because pointing to ‘cloudy’ was a pretty good coverall in this part of the world! – and he was making no improvement at all in the naming of facial features.

I was standing so close to the coalface it was almost impossible for me to see the bigger picture. My life revolved around how much Ian might concentrate on any given morning, or how much self-chatter I had to fight my way through. The fact that he was a reading, talking, thinking child who had a vocabulary of at least 500 words and could do so much was often swamped by how he misbehaved around the house, or by how insecure I was feeling about what I was teaching him.

I approached my ‘teaching method’ from two specific standpoints : ‘Is this useful to Ian’s future?’ and ‘If an Inspector came round today, would I have anything that looked like anything to show him?’** so our progress was a bit haphazard, but progress was made. I had come to love Ian’s capacity to learn – particularly his love of anything to do with words.

So I forged on, reassured by my sweet husband that despite my lack of formal training I really did know Ian best, and reassured greatly by Ian’s own progress. It was not easy, but some days were so rewarding I knew we were on the right track.

I had also kept in touch with Ian’s erstwhile speech therapist, Ruth, and wrote to her –

“…it’s a funny thing, teaching your own child. You wonder time and again whether you’re doing it right. After all, in the absence of any training or qualification, who am I to say what – or how – my child should be taught? But with a child like Ian, when things go well it’s all so obvious. Our lessons are filled with humour, from sly smiles when Ian makes deliberate mistakes to see my reaction, to near hysteria when a difficult task has gone well. It’s entirely up to me what I actually teach my child, so I can examine Ian’s entire range of life skills and see where the gaps are, then make up tasks to bridge those gaps – and decide how I’m going to teach them.

Because Ian’s word recognition skills are so profound, I have taken to using the written word wherever I think it may work (actually I wish we’d tried this years ago). It was taking me weeks to teach Ian the difference between big and little. He just *didn't seem to be getting it. Then I had a brainwave (actually the opposite of a brainwave, a realisation that I was being stupid). Ian can read the words 'big' and 'little', so I wrote them down on a piece of paper and cut them into separate labels. I lay these two labels side by side. "Ian, point to 'big.'" For a moment, the utter simplicity of the task flummoxed him, but then he tentatively pointed to and said the word 'big'. Much praise. "Ian, point to 'little'". No hesitation this time, but he kept glancing at me to check I didn't want anything else from him. We tried it several times, and the task was so simple there couldn't be any mistakes. Then I added the toys I had been using previously. Big Lion, a large cuddly teddy and Little Lion, a small plastic model. By keeping the labels on the table, there could still be no mistake, and suddenly we were getting 100% for an exercise which last week had been entirely unstable.*

I'm still keeping the labels with the toys for the first part of the task, but can now remove the labels from the table, repeat the task, and still get 100% correct responses. Ian is happy because he knows he's getting it right, and I'm happy because I feel like a good teacher.

Ian's also able to say his name clearly ("My name is IAN!"), address and telephone number now, and is learning to give the correct response ("Yes") when I query "Is your name Ian?" We're now working on plurals (one bird, two birdssssss; one car, two carssss) again with labels and toys, and he's beginning to get it. I'm also trying to get him to complete sentences with the appropriate word – 'The …… is in the book' with the options 'tree', 'juice', 'sky' and 'story' on small pieces of paper which he can insert in the sentence; and 'The juice is in the ……' with the options 'bed', 'car', 'bath' and 'cup', etc. Because Ian can read all the words involved, these exercises become a lesson in comprehension – if he didn't understand the sentence, he couldn't give me the correct response – and so far he's doing very well. Certainly the speed with which he scooped up the slip of paper with the word 'story' on it and placed it in the gap provided and likewise put the word 'cup' at the end of that sentence, let me know he understood what I wanted. He then read me the completed sentences and seemed content when they sounded right.

It must be said that when we've romped through his tasks together, and shared so much humour, it gives me a real high because he's making great progress and seems happier within himself than he has been for a long time. In that event, I can't be going that wrong, can I?"

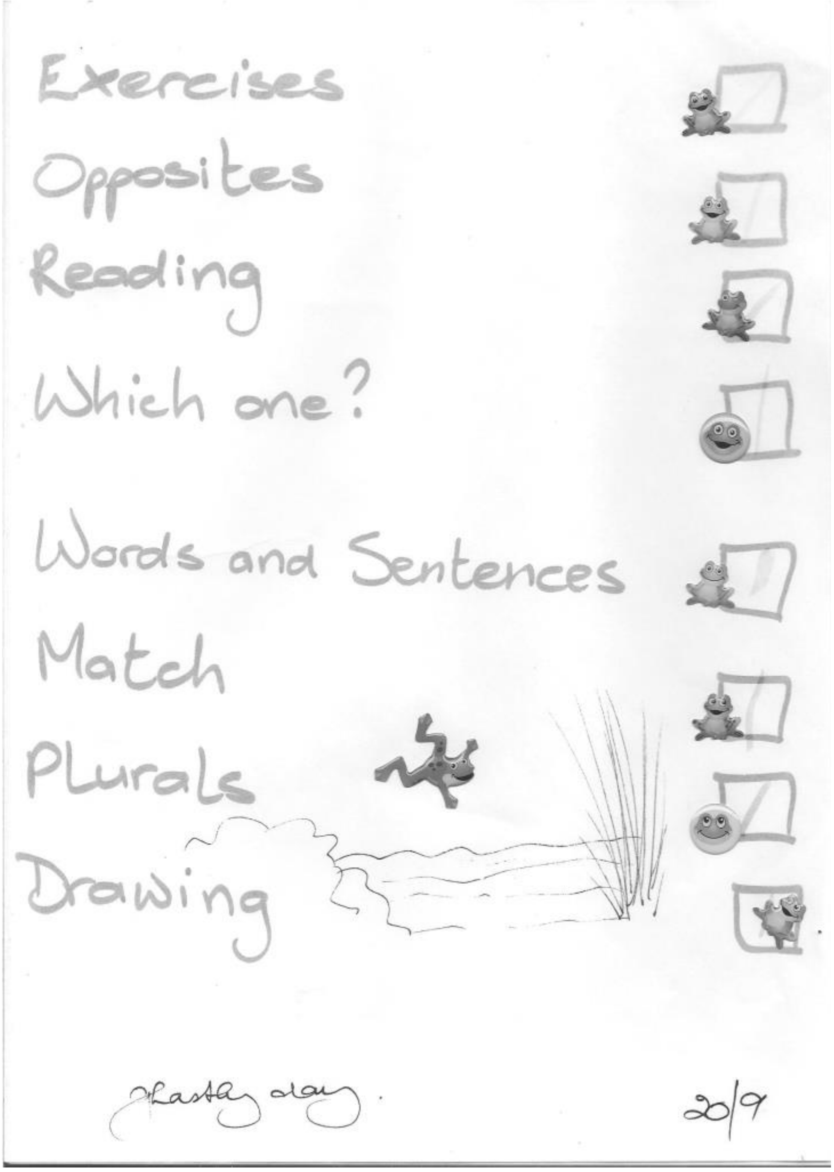
Several months later, during March of 2004, Ian surprised us one evening while I was cooking supper by asking to "go to the classroom". This in itself was a surprise, but not a request I was going to ignore so I took him there. When we got there, he spent a few moments making music on the electric organ, and then I sat him down at the table and presented him a book, which contained words I knew he could read as well as words he was learning. He then produced the best, most fluent reading I had ever heard from him. Sentence after sentence, pointing to the words with his own finger. He barely paused for breath. It was another real *Wow!* moment.

Things were going well with Ian's homeschooling programme, but in order to assess where we stood, I invited Gail – a psychologist who worked at a school for autistic children in Cork – to visit us and assess Ian. Gail came to our house and spent a couple of hours in our little classroom, observing Ian as we ran through most of the exercises we were working on at that time.

Her report arrived a week later and I was gratified to see that she said we were working on "a fairly comprehensive list of programs that address a broad spectrum of Ian's educational needs". Overall, she seemed pretty impressed, which gave me confidence in what I was doing.

Gail also gave me some new exercises to work on with Ian, as well as a specific plan of action to encourage 'classroom self-management' (school self-sufficiency), something her school was geared towards, which would hopefully teach an autistic child how to cope in a normal classroom setting.

As a result of this, Ian was to be presented with a list of work to be done, which he would read through before he started. The list might read Physical Exercises, followed by Reading, followed by a Word Search, followed by Work On Plurals, followed by a Trampoline Time Out, followed by Cutting (I was trying to teach Ian to cut on a line with scissors rather than just annihilating a piece of paper, but his efforts were really haphazard), then Writing, then Sentence Building, followed by a Music Break. Each item on the list had a vacant square on the right-hand side of the page into which Ian stuck a sticker when the exercise was complete. He took to this approach like a duck to water, and also learned (within a week) to say "I'm finished" when a task was complete. All work was placed in order in a pile on his table, so Ian could take it, do it, and tell me he'd done it, with almost no help from me.



Exercises ☑
Opposites ☑
Reading ☑
Which one? ☑
Words and Sentences ☑
Match ☑
Plurals ☑
Drawing ☑

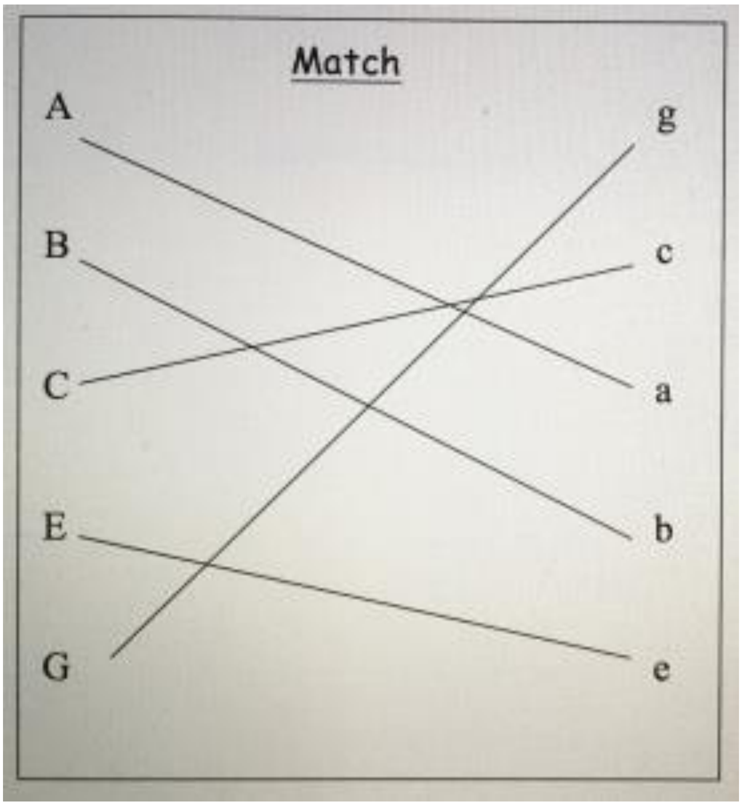
Nasty day. 20/9

Not every day was peaches and cream …

A new thing I had started Ian working on was a Word Search, which was a real breakthrough because it tapped into his ‘splinter skill’, his natural talent for patterns and his love of words. Sitting watching him finding the words from the jumble of letters and marking them off, entirely on his own, quiet and concentrating, wrapped up in his work, was a most wonderful sight. Hearing his soft husky voice saying, “I’m finished” when he was done was just an added bonus.

Then Gail suggested I try working with two lists of work, taking a break after the first list and then returning to the classroom to start on the second list. We worked through the first list pretty well, went into the garden for a swing on the jungle gym, and then returned to the classroom for list number two. Ian shutdown completely! He looked at the new list with absolute disgust and refused to co-operate at all. The minutes ticked away … his opinion didn't improve. It was a pity, really, because he had started the day in excellent spirits. The second list had to be abandoned; it was just too much.

I had started a new task with Ian, which involved two columns of things down either side of an A4 piece of paper, with the word 'Match' written at the top of the page. They could be numbers, letters or pictures to start with, the order on each side of the page was different so that the child had to draw a line to connect the matching numbers/letters etc from one side of the page diagonally to the other, like this:



Ian loved this, and quickly romped through the easy ones. So I began to make the task more thought-provoking, listing animals with their babies – cow/calf, dog/puppy, duck/duckling, etc, concepts like bed/sleep, cup/juice, chair/sit, or plurals like goose/geese, foot/feet, house/houses, tooth/teeth, etc. Ian had no trouble with these either, so I took it a step further with more abstract ideas like sky/blue, grass/green, sun/yellow, clouds/grey, flowers/pink. This last one really caught Ian's attention and he spent quite a while reading it but when he saw the connection, he was away. It was marvellous to watch the concentration on his face and to know that he was actually really thinking about things. It was hard to find tasks which captured Ian’s interest, and I was very grateful for these simple yet thought-provoking exercises.

* * *

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* Because of Ian’s toe-walking, his hamstrings were exceptionally tight. I worked tirelessly to help him stand flat on his feet, and to gently stretch the muscles on the backs of his legs to make this easier for him.

** Of course a School Inspector never appeared. I realised fairly quickly that by removing my child from the system, he had become just ‘one less autistic child to worry about’, and no one seemed to care what we were doing or how we were doing it.

Extras

Two more short snippets of video footage – and yes, they're from the same day as last time. I didn't often video Ian in school – he found it quite distracting having a camera on him – just when I wanted to keep a record of what he was doing, and particularly, what he was doing well.

https://fromtheinsidedotorg.files.wordpress.com/2020/09/img_8547.mov

At the beginning, you can hear Ian reciting from Disney's Alice in Wonderland – the Red Queen asks Alice "Are you ready for your sentence?" and Alice replies "Sentence? But surely there must be a verdict first!" Ian was playing with the intonation of the two words. This task was one which I designed myself – a sentence with a word missing, and Ian had to complete the sentence choosing from four options.

https://fromtheinsidedotorg.files.wordpress.com/2020/09/img_8546.mov

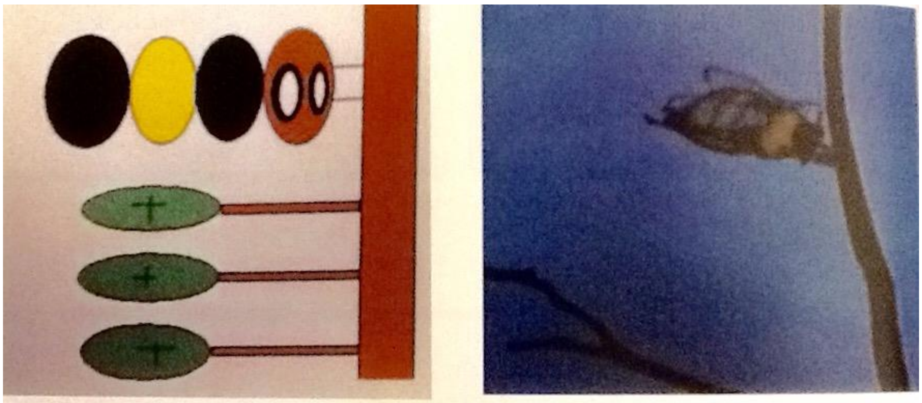
Match exercises were almost a reward in themselves, Ian enjoyed them so much. I tried to make them progressively more challenging, to keep Ian's interest and make him think.

Chapter Sixteen

While I was home-schooling him, Ian had a computer in his bedroom. It was disconnected at night but he had free access to it during the day when he wasn't in the classroom. He had a limited range of programmes on it, but what he managed with those was nothing short of extraordinary.

The programme Ian loved most was 'Paint', a programme which allowed him to make pictures using squares and circles, which he could move around to create a picture. Changing the sizes of the shapes and filling them in with colour meant Ian could reproduce – recognisably – scenes from some of his favourite DVDs.

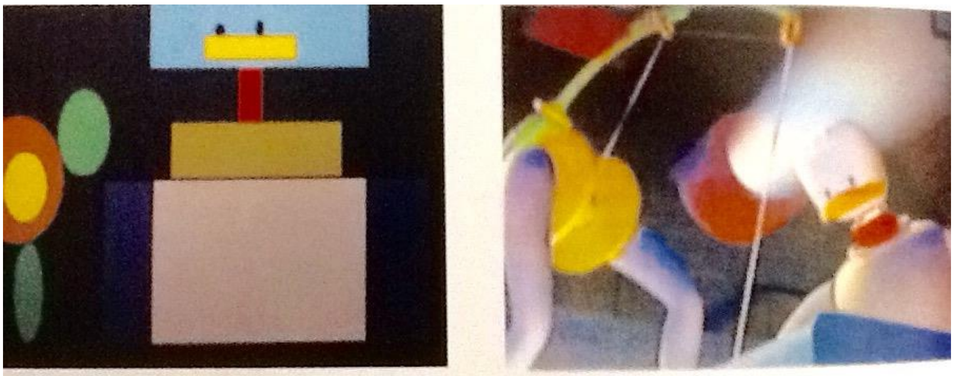
It took me a while to realise what he was doing. It was only when I saw his bee picture, and recognised it as a scene from Winnie the Pooh, that I understood what he was up to. When I looked at the film of Winnie the Pooh myself and paused it at the scene Ian had recreated, I was astonished at what he had achieved using only circles and squares.



The Many Adventures of Winnie the Pooh (©Walt Disney)

This led me to look more closely at all his other pictures as well. If this one was so accurate, perhaps others were too.

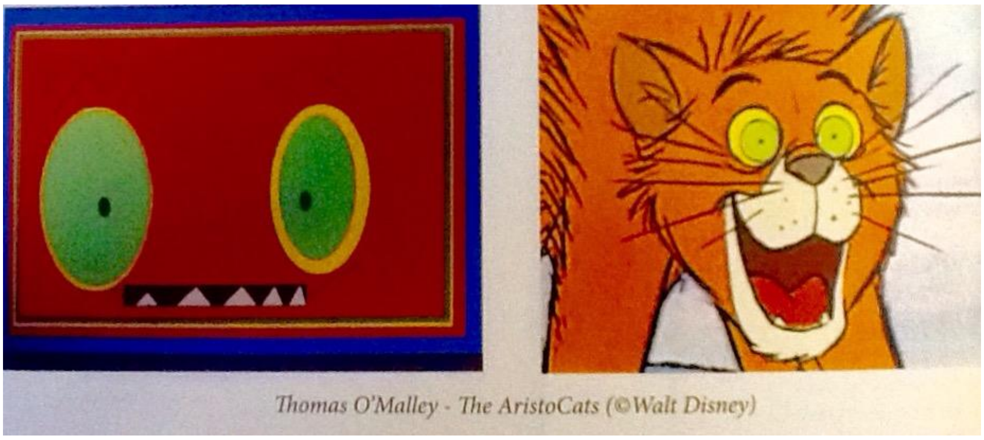
There was a certain amount of guesswork involved because Ian wouldn't identify where the picture came from, and although his very artistic older brother, Rory, recognised several, we never found out the root of many of them.



Ducky - *Toy Story* (©Disney Pixar)

Sadly, in the end we had to take Ian's computer away from him because he seemed fixated on only one picture which he created over and over again. It was a close-up of Thomas O'Malley from The AristoCats, in the scene where the tomcat leaps on the milk wagon and terrifies the driver, so Duchess and her three kittens can get aboard and journey back to their beloved Madame in Paris.

It was only months later that I realised that Ian hadn't been recreating the same picture, what he had in fact been doing was minutely changing each picture, and *recreating the DVD footage, frame by frame. He was creating his own* *animation, which he could flick through on his computer, one picture after another, replaying the scene for himself!*


Thomas O'Malley - The AristoCats (©Walt Disney)

Aside from the computer – which had been a very successful gift – we struggled every year to find Ian a birthday present he would enjoy because his range of interests was so narrow. Then we had a brain-wave and for his birthday that year, we gave Ian a keyboard.

At first, he played strange, haunting, other-worldly experimental music. Plinky-plonk tunes that had neither beginning nor end. This kept him busy for quite a while before his interest waned.

Then he went back to it, but this time spent hours shaping chords. He found three that satisfied him, and he repeated these in a sequence for many weeks. Then his interest waned again.

When he came back to the keyboard, he seemed to have a purpose. He fiddled with the notes until he could produce a succession of chords. And it was only when I heard the full progression that I realised what he was up to. The music he had successfully recreated, without training or assistance, was the background music to the opening number in the film, 'The Lion King'.

And then, wonder of wonders, one afternoon I heard him playing the chords and very quietly, entirely to himself, he sang over the top – *"From the day we arrive* *on the planet and, blinking, step into the sun / There's more to see than can ever be seen, more to do than can ever be done…"*

I stood outside his bedroom and cried. The beauty of that moment was so intense, so huge, and simultaneously so frustrating, I didn't know what to do with myself. It was so perfect I was breathless, but why-oh-why didn't I have some recording device with me! I knew I might never hear Ian do this again, and this precious moment would be lost forever.

In his teens, of course, Ian's voice broke and he could no longer sing all his songs the way he wanted to. His near-perfect pitch was deeply offended by his 'new' voice so he stopped singing completely, which was really, really sad.

* * *

Chapter Seventeen

But getting back to Ian's schooling, every now and then I would be brought up short by the realisation that there was a marked hole in Ian's abilities. I realised one day that he was using his name as a key, and that he would only respond if his name was included in the instruction. For example, if I said to Ian "I love you", he would ignore me, but if I said, "I love you, *Ian*," he would answer, "I love you too, mummy."

This was very nice and very cute, but what it meant in real terms was that when we were out and about, he wouldn't greet anyone because strangers didn't know his name. They would greet Ian with a cheerful "Good morning" without giving him the hook ('Good morning, *Ian*') for him to hang his answer on.

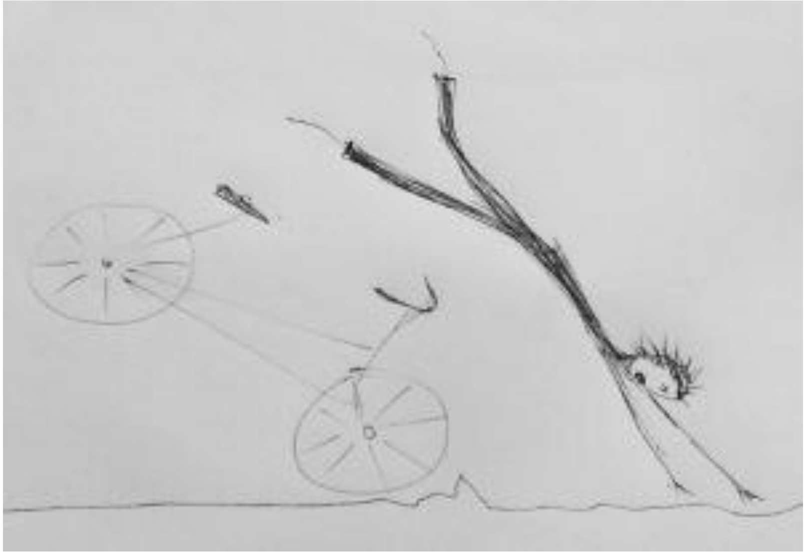
This was quite important as the Irish adore children and they will always greet a child. To not respond is very rude and even when I explained about Ian's condition and they understood completely, it was still embarrassing (to me) when it happened.

Once I had realised this, I started teaching Ian to respond to me when I only said "Good morning". At first there was a deathly silence while he ignored me completely. Then he realised that I was actually waiting for something. It took a while, but we got there in the end and he did start to greet me in return. I hoped that when the lass at the supermarket checkout greeted him, Ian would be able to respond appropriately instead of ignoring her.

He did, but I don't think she quite caught his "*Good morning, Mummy…"*

In one of our earlier speech therapy sessions, the therapist had shown Ian a picture of a chap riding a bicycle and the front wheel of the bike had hit a rock, so the back end of it was up in the air and the chap was falling forward. She had asked Ian to explain what was happening in the picture. After a deafening silence of several long minutes, Ian summed up the situation most succinctly. He said, quite simply, "Oops!"

I thought it was brilliant.



A quick sketch approximating the picture
(and yes, I know there are no pedals on my bike!)

However, it did bring to light a gaping hole in Ian's knowledge – the ability to explain anything or to make comment on anything. So I started working on comprehension exercises with him, at that stage fully prompted because he didn't have a clue. Reading him a story three sentences long and then expecting him to answer questions about that story was much like waiting for a rocking horse to neigh. It highlighted the enormous hole in the autistic mind, the inability to comment on something or to think in abstracts.

Ian looked completely bored by the whole idea and if I couldn't get him interested in it, how was he ever going to progress in this area? It was and has remained a frustrating problem area.

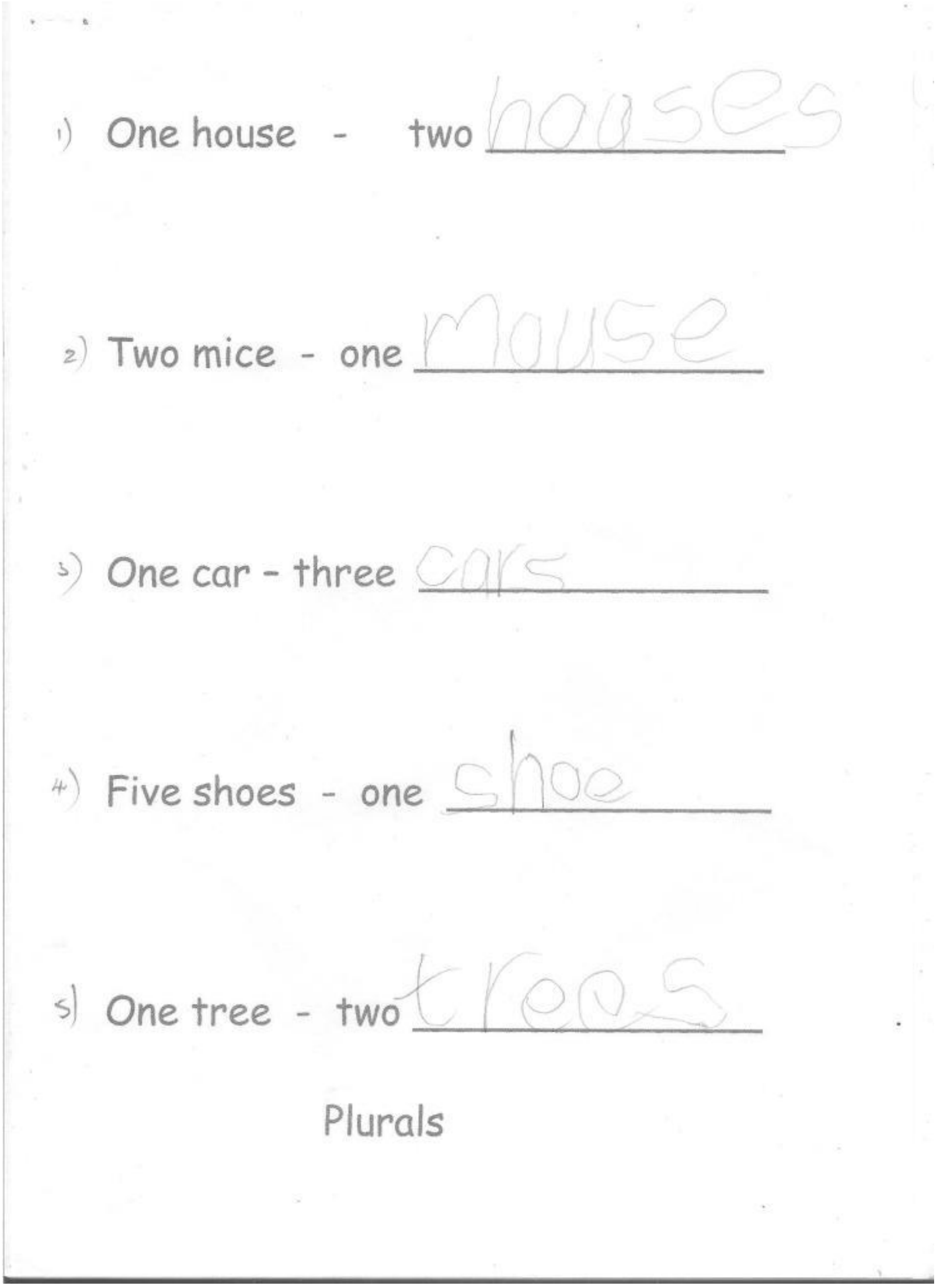
But the highlights were so all-encompassing! Small though they were, they were huge to me, desperate as I was for any sign of progress. I wrote to Gail in July of 2004 –

"For the first time ever, today, Ian gave me a weather report! He looked out of the window and, with no prompting whatsoever, said "Grey. Today it's cloudy!!" I was so surprised I nearly fell off my chair. Whoopee!"

And later that year, I wrote again to Kirsty, filling her in on Ian's progress and the things I was teaching him –

"…I found myself taking a step back from Ian's school work the other day to look at how far he's come in the year I've been teaching him. Okay, so it's not miraculous or anything like that, but he's learnt to write again – and neatly at that – and he's learnt some elementary sums (he knows that 1+1=2, and 2+1=3, that 1+2 also =3, that 2+2=4 and he'll hazard an accurate guess that 3+2=5). He's so chuffed when he gets it right! He's also writing his plurals now – I have pre-prepared sheets on the computer which I change daily and print out for him – one goose, two ______, three feet, one _____ – so I present him with a list of five or six different ones and he writes in the correct answer. He's also doing sheets of opposites, and completing simple sentences.

I've finally got him to the stage where I can show him a picture card and ask him "What is the girl doing?" and he'll answer "The girl is reading … the book" or "What is the boy doing?" and he'll answer "The boy is knocking on the door," which *makes my heart soooo glad. I whoop and cheer and clap my hands, and Ian sports this little smile like he's secretly really, really pleased."*



1) One house - two houses

2) Two mice - one mouse

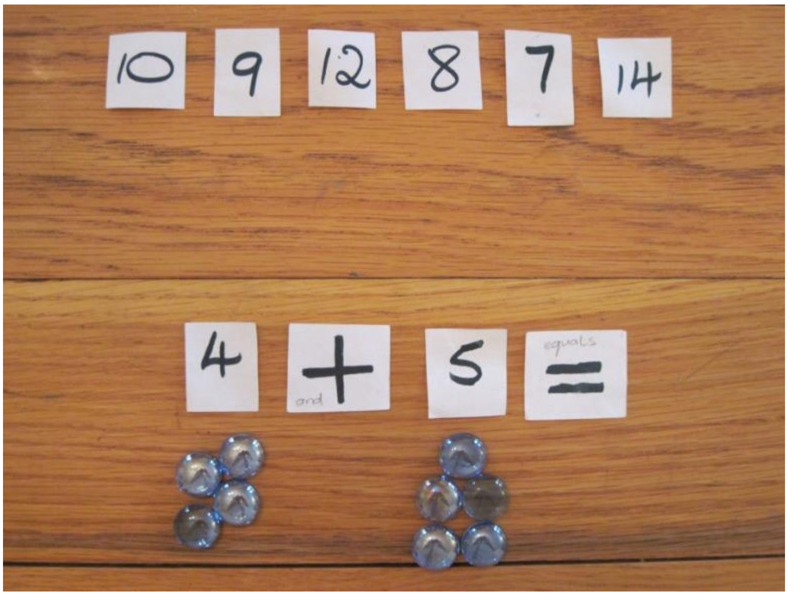
3) One car - three cars

4) Five shoes - one shoe

5) One tree - two trees

Plurals

A simple task – but already I was asking Ian to work both ways, from singular to plural, and from plural to singular



If Ian was unsure of the answer, he could count the blue beads and get the total of the sum. He would then move the beads to the 'total' position and choose the answer from the row of numbers above the sum.

(All hand drawn on paper)

* * *

Chapter Eighteen

Was it all as good as it seemed?

Hmmm…

In some ways, yes, it was. Ian was learning well in school, although he was testing my patience to the limit with his stubborn silences and his determination to fight me every step of the way. Sometimes he wouldn't let me get a word in edgeways while he chatted endlessly to himself, driving me mad with his incessant noise. Despite my best efforts to encourage him to join me in our world, he seemed determined to remain in his own one. In the face of this, it was very hard to remain cheerful, optimistic and enthusiastic.

However, there could be no denying that Ian had progressed hugely since his days at the Autism Unit and educationally he was a different child. He had learned so much.

But there were many things wrong with our set-up, too. I had to acknowledge that trying to do everything myself without even looking for help was an enormous strain. It often kept me awake at night, and I would lie in the dark worrying about what to teach Ian next and how best to approach it.

Neil always supported me one hundred per cent, although there was little he could actually do other than give me lots of his wonderful reassuring hugs. He knew the strain I was under, but he believed in what I was doing and loved it when I shared Ian's daily work with him, showing him all the things Ian had done, and commiserating when I vented about all the things Ian wouldn't do. The Autism Unit experience had left us both scarred by the speed of Ian's deterioration, and we were determined to protect our child from well-meaning but misguided help.

Was this arrogant? Of course it was! But as Ian's parents we knew we had to give our child the education we believed he deserved, and his continued improvement justified our decision.

At the end of August that year, I wrote to Kirsty –

"Ian was doing particularly well at the end of July, before I took a much-needed break from teaching him. I had managed to formulate tasks that combined reading, comprehension and writing – giving him short sentences, which were incomplete, and requesting him to write in the required word. Quick example: "I like to sleep in my ____" and Ian would read the sentence, give the correct word 'bed' and write it in. I also write lists of "The opposite of up is ____" which Ian will read and complete, again writing in the missing word. He knows a lot of opposites now, which makes my job that much easier.

I'm also having fun giving him sheets of paper with "Draw a happy face" written at the top, with a big circle in the middle of the page, which Ian would happily fill in with appropriate features. His 'sad' face is brilliant, a real downturned mouth and sad eyebrows! His cross face is great too, with a zig-zag mouth and strong angry eyebrows. I find it interesting that his facial interpretation centres around the eyebrows."

Ian remained himself. Out of school he was bright, sunny, contented and loving. What a sweet kid. Mostly I think he enjoyed school unless the work was particularly taxing, and some days he was a pleasure to teach.

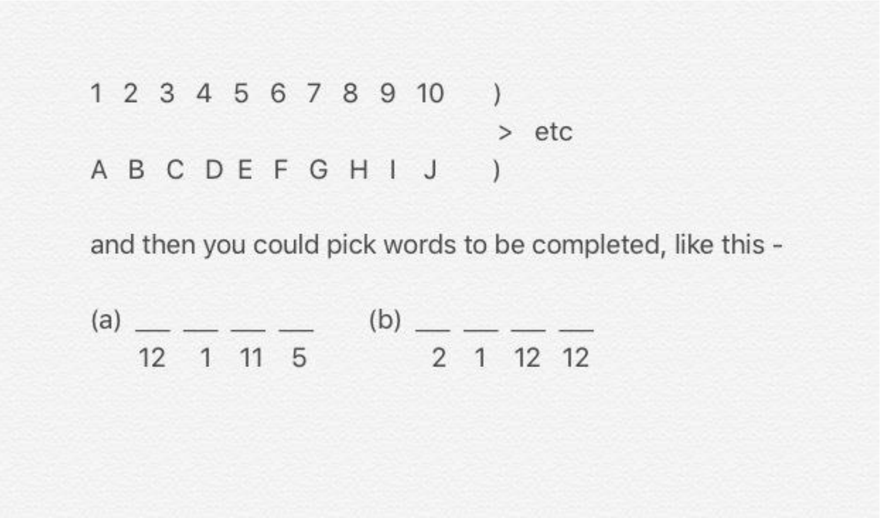
It was just those days when he didn't want to work and retreated to his own quiet place inside his head that were really trying. If he was in a mood to be passive, nothing I could do would get him out of it. I would sit looking at him wishing I could squeeze something out of him.

Sometimes I would lay my head on my arms on the table and pretend to cry. Ian would listen for a while, then lift my head with both his hands and look at me quizzically. *Do you mean it?* his eyes would ask. On a good day he would say out loud "Do you need a tissue?" and I'd reply "Mummy's sad, Ian. Please answer the question. Look at the picture. What is the boy doing?" and without hesitation (on a good day) he might reply "He's sleeping". And I'd thank him and praise him and move on, and he'd retreat again and refuse to answer the next question, and I'd think, *I'm going to go mad if this keeps up*.

But then, conversely, I could put a piece of paper in front of him marked Plurals with single words on it – calf, knife, foot, mouse, tooth, etc – and say "one calf, two …" and Ian would write the correct answer, and then the answers to all the others without prompting until the list was complete. Then he'd say, "I'm finished" and lean back in his chair. Gold star stuff!

There were occasional surprises, too, when the growing-up-Ian displayed itself to us. He was much more his own person and often very determined to have things his own way. If, for example, you didn't supply his juice quickly enough when he'd asked for it, he might put his face right in front of yours and say slowly and clearly (as if *you* were mentally challenged), "Please. May. I. Have. Some. Juice." and then, if you didn't respond within the two nanoseconds Ian had allocated to this task, you might just get a mug slammed on the table in front of you, in case you *still* hadn't got the message!

He was doing so well with me in school I started him on a new task, something I'd seen in a school exercise book, which showed a line of numbers with letters underneath, like this –



1 2 3 4 5 6 7 8 9 10)
> etc
A B C D E F G H I J)

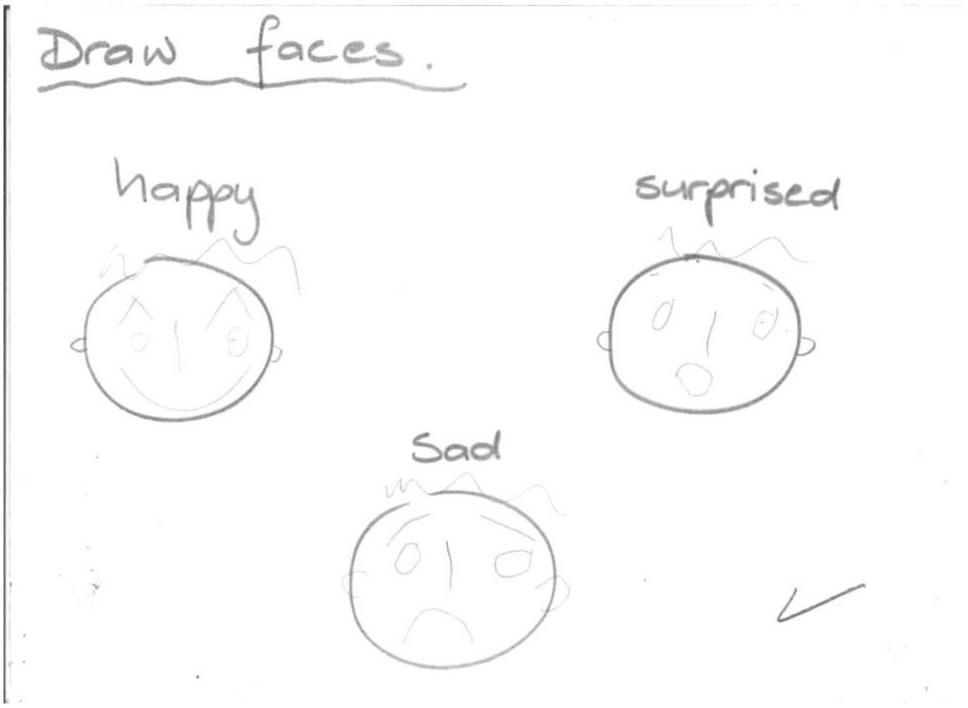
and then you could pick words to be completed, like this -

(a) ___ ___ ___ ___ (b) ___ ___ ___ ___
12 1 11 5 2 1 12 12

It took Ian a while to work out what was required, but once he realised that he could make actual words (most of which he could read), he got quite involved.* I loved watching how his eyes moved from the blank line to the number underneath, up to the corresponding number and then down to the required letter. He then wrote the appropriate letter on the space provided. It wasn't a difficult exercise, but it did require some concentration. Once Ian was managing single words, I started making short sentences, but then he lost interest and we had to move on to other things.

We were also working on the concept of 'bigger' and 'smaller', and I would draw quick sketches of things like a big butterfly and a small butterfly, or a big heart and a little heart, and at the top of the page write 'Which butterfly is bigger?' or 'Which heart is smaller?' and Ian then had to point to the correct one and write 'this one' underneath it. This went pretty well; he earned himself a few gold stars for these pages. From this, of course, we moved on to 'small', 'bigger' and 'biggest' and 'big', 'smaller' and 'smallest' with equal success.

All in all, Ian's education progressed, he was learning new things, and we were having fun into the bargain.



* Ian learned the ‘number alphabet’ so well, he started ‘writing’ words on his calculator. He would do it so quickly it was virtually impossible to see what he was up to, but occasionally I could catch him with a speedy “What does that say?” and he would read the ‘word’ to me. Once, he told me “Walk” – he’d put the numbers 2311211 into his calculator – and another time, it was “Juice” – 1021935. Today, he can read the numbers as easily as you or I might read the alphabet.

This was the easy version, though. I used other tasks where the alphabet corresponded with random numbers – like an adult ‘code words’ game. Ian got into these, too, but of course he always preferred the easy ones.

* * *

Extras

I include here two more video snippets (slightly longer this time) which will, I hope, give you more insight into how we worked together and what we did.

https://fromtheinsidedotorg.files.wordpress.com/2020/10/video-1602429772.mp4

In this fun task, Ian would engage in appropriate turn-taking and come up with words beginning with the correct letter, then write them down. He also had to read the word I wrote. He frequently came up with words I hadn't known he knew, which was always a surprise.

https://fromtheinsidedotorg.files.wordpress.com/2020/10/video-1602430546.mp4

In my endless quest to improve Ian's speech, I decided to provide him with responses – in answer to set questions – which he could learn and use as necessary. He had different sets of sentences for different activities in various rooms in the house. As so often happens, doing the task once was easy; doing it again was more of a challenge.

I think it is important to stress again that I wasn't working from a textbook or following a set programme. I read a great deal, and I did a lot of thinking – usually in the middle of the night.

It was one thing to decide "Oh, I need to teach Ian such-and-such", but quite another to reduce that task to its barest essentials and formulate a path of progression which would take Ian from nothing to the final goal. And *progression* was what it was all about. I aimed many tasks at Ian's strengths (to keep motivation high), and I constantly reviewed his progress. *Was he getting it? If not, why not? Could I teach it another way?* etc.

I taught Ian things I felt he *should* know, and because I made up exercises as I went along, I was able to teach them in a way I knew Ian would understand. Because he was so clever, if he didn't get it, I wasn't teaching it right. It was pretty obvious. These snatches of video are only ever a tiny snapshot of one morning's work, mere seconds of several hours' concentrated effort, every weekday of every month.

Thankfully, Ian was a wonderful pupil, and I hope that the fun we had together and the joy it gave me to teach him comes across in these video offerings.

Chapter Nineteen

Ian’s speech was improving slowly. He knew many words but consistently refused to use them. This was deeply frustrating for me, knowing that he had such a large vocabulary in his head that he wouldn’t use. I had listed the words he had learned, and knew that he had more than 550 words at his disposal, and yet his conversation revolved around set requests like “Toy Story video please, Mummy” or “Push me, please” when he was on the swing. He could express his needs and wants, but appeared not to want to learn to speak more than was absolutely necessary.

However, there were occasional surprises, like the day I took Ian for a walk in a nearby pine forest.

The forest floor was very damp from all the recent rains we’d had, but the mossy tussocks provided a dryer path, as long as you could keep your balance.

Ian, of course, had no trouble at all – well, he could stand upright on the back of his rocking horse, rocking, whilst reading a book, so obviously his balance was fine! Mum, on the other hand, falls over at the drop of a hat, or in this case, the shifting of a mossy tussock.

Thankfully, I fell into a dry ditch, not a wet one, and the moss was very comfortable to land on. But what took me by surprise after I'd landed was Ian's little voice saying "Oopsie!" as he surveyed his Mum in a heap on the ground. His "Are you okay?" as I got up was so appropriate I hastened to reassure him that I was, surprisingly, quite fine, no damage done, whilst privately I marvelled at his concern and his compassion, and knew I would never forget the moment.

We continued our walk over the squashy moss, punctuated by Ian saying "Oops!" every time his foot moved when he didn't expect it to. It was really very funny.

One afternoon, Neil and I were sitting at the kitchen table discussing Ian's work and his progress, as well as his occasionally extraordinary behaviour, his growing up, etc, when Ian walked through the kitchen and opened the back door. For whatever reason, I didn't want him to go out and said, almost to myself, "Ian, please stay inside" to which my darling, pliable, amenable little boy shouted "I want to go OUTside!" – and promptly did – thereby resolving something Neil and I had just been discussing, i.e. did Ian actually understand the concept of opposites?

Ian was finding quite a voice for himself.

Then one day Ian brought me his barking dog, looked at me intently and said “Red” with meaning. I looked at the dog. It was brown, black and white, with no visible red. Perhaps its tail wasn’t wagging again. I pressed its paw to make it bark. Nope, the tail was fine.

“Red,” said Ian, again. Then I spotted a length of black cotton. *Aha! Thread!*
“Fred,” said Ian, amending his request.

“Fetch me the scissors, Ian,” I told him.

He romped off to the kitchen and brought back the tin opener. Not quite what I was after, but a reasonable alternative. No good for cutting the ‘fred’ though.

“Rory!” I called to the kitchen. “Give Ian the scissors, please.”

Within seconds Ian romped back into the lounge with the scissors and I cut off the offending thread.

“All fixed,” I told him.

Ian then examined his dog from every conceivable angle, and disappeared back into his bedroom.

Ian’s thread fetish became slightly scary after that because he would spot an offending length of something and get the scissors himself. The kitchen scissors were about seven inches long, large and strong, for kitchen use. I made a point of following Ian back to his room when he took the scissors, just in case.

One day Ian ran into the kitchen saying, “Scissors please, Mummy” and taking them off the hook, he ran out again. I followed him – running with scissors, honestly! – wondering what he’d seen.

I found him sitting on his bed, aiming the scissors at his face. When he saw me, he opened his mouth and pointed to a wobbly tooth.

“Scissors… please, Mummy.”

Horrified, I gently took the scissors out of his hand.

“Oh nooooo, my child. No scissors for that. I’m sorry, but no. Not this time.”

He looked quite disappointed. He sensed that his tooth was hanging by a thread; what was the difference? Later that evening, he pulled the tooth out with his strong nimble fingers, and thankfully didn’t try to damage himself again. But boy, that was one scary moment.

And then there were the exceptional moments when Ian appeared to have leapt linguistically in a direction no one could have anticipated. In December of 2005 I wrote to his erstwhile speech therapist, Ruth –

“I meant to tell you about an incident which happened the other evening. I was watching TV, one of these ‘reality shows’ about a group of people walking through a desert – all of them complete novices – none of them possessing, apparently, the strength of character to avoid whining or complaining – you know, the kind of TV which seems so popular these days, and I was just about to turn it off when Ian appeared at my shoulder, looked at the telly, and said, clearly and distinctly, “Prehistoric man.”

I looked at Ian, looked back at the TV and had to admit that yes, one of the fellows did have a vaguely Cro-Magnon face, but I wouldn’t go so far as to call him ‘prehistoric man’, and I looked back at Ian and queried “Prehistoric man?” His mouth curved into the most gorgeous smile as he glanced at the telly, and he repeated it looking straight into my eyes: “Prehistoric man!” And then he was gone.

Good grief! This happens every now and then, a bizarre stunner which we cannot take credit for. God knows where he got that one from. ‘Prehistoric man’? It’s not something which one constantly uses in normal everyday conversation, now is it?

Just wanted to share.”

I had long since realised that Ian *saw* far more than the rest of us, *heard* more than the rest of us, and quite possibly *remembered* more than the rest of us; that his mind probably held so much information I was no longer surprised that he couldn't always retrieve the word he needed. We dump information all the time. Imagine if you couldn't do that, if all the information you had *ever acquired*, all the things you had *seen* and *heard*, sat cluttered in your head, forever. It explained much to me about why autistic children needed to 'zone out'.

Then again, there were times when Ian's use of language was so perfect it seemed almost impossible.

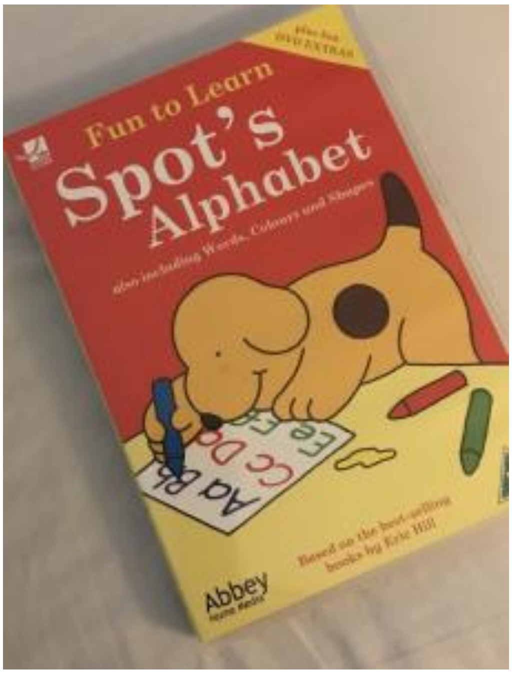
One day, I was sitting at the kitchen table playing a game on my laptop, supervising Ian who was watching a DVD of The Sword in the Stone. Neil made a comment about my figure, saying that a near neighbour who had stopped at the gate for a chat while we were gardening earlier in the evening must have been envious (What a sweet man. Surely it was a trick of the light, darling!), and I countered with the comment that I was envious of her because she had just told us she was expecting her third child, and I would give anything to be pregnant again. And with exquisitely perfect timing, Ian, very softly and almost to himself, said, "You scare me."

Well, Neil and I just burst out laughing! Neil agreed wholeheartedly with Ian, saying that when I made statements like that I was particularly scary, but what a moment. Heavens, it was funny!

But where did he get *that* one from? We had no idea. We couldn't think of a video it came from, and he certainly hadn't heard it at home. One just had to wonder. It wasn't just appropriately timed, it was an appropriate comment – in fact, Ian's first joke when you come to think about it. Oh me, oh my. Out of the mouths of babes and autistic children…

Of course, as a parent there were times when we had to use his own language back at him, like the time Ian was fixated on an alphabet song from one of his Spot DVDs, and often delighted us with "A is for Acrobat, B is for Ball, C is for Car, D is for Dolphin…" straight from the song. On this one morning Ian was determined to leave the breakfast table long before he'd finished his breakfast, and I was equally determined that he should sit. So I quipped "P is for Please, E is for Eat, Y is for Your and B is for Breakfast. Please Eat Your Breakfast!" And the most beautiful little smile came over his face as he worked through what I'd just said. He gave me an amused glance – I can only call it that – sat back down, and started to eat again. It was the most wonderful momentary connection, and a great start to my day.

What a kid!



Chapter Twenty

In one of her marvellous letters, Kirsty had asked me if there was anything I would do differently, if I had the chance to start all over again. I spent a long time thinking about this one. My natural introspection meant that I had considered this question before many times, and with hindsight always so much clearer, I had to be careful not to beat myself up about mistakes I might think had been made along the way.

I wrote to Kirsty –

"What would I do differently if I had my time again? A few things that I can think of now. As a mother I'd be more forgiving, less demanding. I've become so, but I didn't used to be. I mean more forgiving of the child's autism, his lack of control over it. We've always treated Ian like a normal kid with odd behaviours. This, in retrospect, hasn't always been the right way. Mostly, but not always.

I'd have let my child achieve more unaided – it's too easy to assist all the time, and the child never learns how to do it him/herself. Standing back and just waiting is the most powerful tool you have. As long as the child actually knows what is required, it'll come, eventually. I once made notes for forty minutes whilst waiting for Ian to put his socks on. He went through his entire repertoire of avoidance techniques, but I wouldn't be moved. I refused to do it for him and forty minutes later he did it for himself as I had always known he could.

As a tutor I'd have started with the written word far sooner with Ian. I have video footage of him, even within the first few months of therapy, trying to look at the words on the back of the flashcards, more interested in the words than the pictures. He could read long before we gave him credit for it.

I'd also give the child the tools and the confidence to contradict me. One spends too much time teaching positives – 'What is this? Yes! It's a cow!' or 'Point to the shoe. Good pointing!' – we don't arm the child to be able to say 'Rubbish! It's not a horse, it's a tractor!'"

It was an interesting exercise, thinking like this, because it made me face up to a few home truths at a time when Ian was going through another difficult patch. His latest behaviour to emerge was a violent twitch, which I truly could not cope with. All the other behaviours he had been through up to that time had been either easily controlled or easy to ignore – the hand flapping, the noises, even the face pulling – but this one I just couldn't take. To hold his hand and feel him violently twitching his fingers was really awful. I prayed that it would pass soon.

One morning, after a successful but difficult lesson at the kitchen table (successful because his work was good, difficult because he kept trying to tune out and I had to work hard to keep him focused), we went for a walk along the lane. It was a beautiful autumn morning, with a soft breeze, high clouds, occasional sunshine, and birdsong everywhere. Holding Ian's hand as we walked together and feeling him violently twitching his fingers every few seconds depressed me almost more than I could bear.

We walked down a track through a little forest which has a small stream running through it. It was a wonderful place to walk because I could let go of Ian's hand and let him run free without having to worry about traffic – there was nowhere he could go but on the path. When we came to a more open area where Ian liked to throw little stones into a meandering stream, I watched as he stepped onto a large rock in the middle of the stream.

Then, deliberately and with forethought, he jumped into the running water. Well, he was wet and there was no point getting het up about it, so I let him get on with it. Occasionally he looked my way, and I smiled and nodded my approval.

For forty-five minutes, he played in that little stream, kicking the water, jumping in it, splashing it with his hands. And for those forty-five minutes, he was blissfully happy. Smiling and giggling to himself, he played and played. And while he played, I watched and walked in large silent circles on the forest path, trying to come to terms, yet again, with what it means to have an autistic child.

* * *

Chapter Twenty-One

Ian was growing up.

At nine years old, his behaviour swung between the perfect child we knew and loved, and an utterly outrageous child we didn't know at all. He was just coming out of a dreadful phase where the head hitting, hand twitching, shrieking, Teletubbie-thumping had been at an all-time high. I eased off doing school with him because my presence seemed to make his behaviour worse – and I couldn't blame him, he must have been thoroughly sick of me – and when he was at his worst there was no way I could get through to him in any event so it was pointless trying.

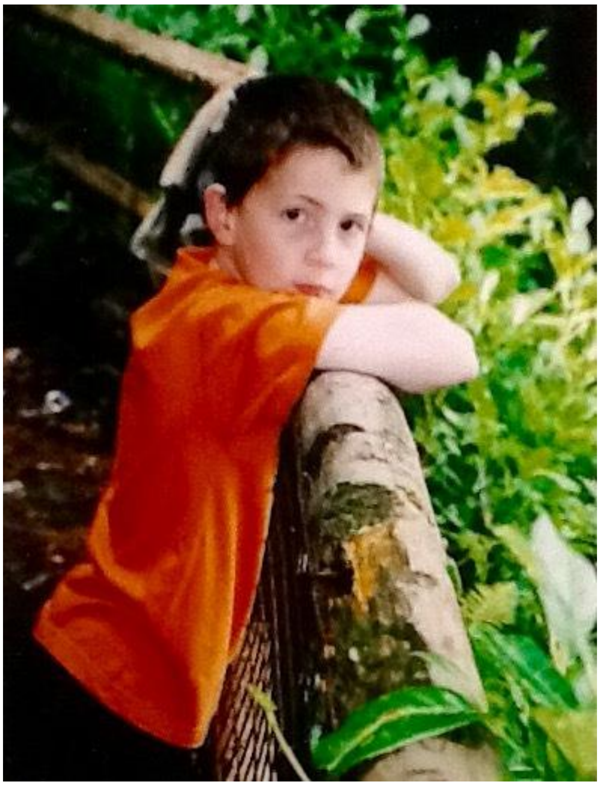
As the days passed, though, he seemed to be improving. He was happier within himself, and calmer all round. Until one morning.

I had suggested that Ian get dressed – a normal everyday suggestion, put to him in a normal everyday way – and I knelt down on his bedroom floor to help him, whereupon Ian threw himself down on his bed, thrashing like a wild thing. Then he launched himself at me and *screamed* directly into my face. Shrill, long, and very, very loud. It was really quite shocking.

I looked at him sternly when he'd finished and in an upset, constricted voice I said to him, "How *dare* you scream at me? I don't get to scream at you. *I'm* the one who wants to scream …"

Then we both sat in silence. I think I was pinching the bridge of my nose and had my eyes closed (oh, how I longed to be far away at that moment) when all of a sudden this husky little voice next to me said, "I'm sorry."

Well, I was pretty stunned but I immediately gave Ian a big hug and told him, "It's okay, my boy. We're both alright now." And he hugged me back. Then he took his pyjamas off and was happy to get dressed, and I was left thinking *Gosh, the things that happen*.



Later that evening I took Ian into the bathroom to brush his teeth. I usually sit on the toilet seat with Ian standing in front of me, but that night when I sat down Ian threw his arms around my neck and clung to me in a really tight hug. I manoeuvred him into my lap and hugged him back. It really gets me when he does this, and I had trouble breathing past the lump in my throat. Then a little voice from my neck asked, “You okay?” which choked me up even more, but I managed to reassure him that I would be fine.

When I opened the bathroom door, Neil was standing there looking a bit concerned. “You were gone for so long I wondered if everything was all right,” and I smiled sadly at him.

“We’re fine,” I said. “Ian wanted hugs.”

This didn’t happen often, but in some strange way it was almost like the opposite of autism. Ian wasn’t shutting me out and holding me at arm’s length; he wanted to join us together, in that moment, in one world, where all was straightforward and clear.

And at that moment, in that hug, I could make it happen.

* * *

Chapter Twenty-Two

Towards the end of September 2006 I had a couple of extraordinary days with Ian when there wasn't one single word of self-chatter throughout his session. Not one squeak out of place. It was unheard of! I was so excited by this, I wrote to everyone I knew. I was particularly pleased because I had started some new exercises with Ian, and he usually reacted quite badly when I introduced new things.

The first new task was one of those things which had been suggested by the Speech Therapist and something which I had tried with Ian over the years, even as I wondered about the importance of it : Rhyming words. Did this task really constitute something my son should learn? I struggled to see the point of it; I doubted Ian would ever start writing poetry …

Anyway, there I was with brand new flash cards showing, say, a picture of a dog with the words "This rhymes with …" next to it. I looked at these cards and wondered how I should teach Ian this.

I sat with him at the kitchen table, armed with a sheet of paper and Ian's pencil. I quickly wrote the words 'hair', 'frog' and 'mouse' underneath each other.

"Okay, Ian," I said, turning to him, "which one rhymes with Dog? Which one sounds the same?" and at the same time pointing with the pencil to the word 'frog'. Good ol' error-free learning! Of course, Ian said the one I pointed to, and then I swayed from side to side in my chair, holding the flash card and chanting “dog… frog… dog… frog…” and Ian joined in with a smile on his face.

Then I showed him the card with the picture of the kite on it and wrote ‘light’, ‘chair’ and ‘table’ on my piece of paper. He almost got it but I guided vaguely with the pencil. Bingo! Again, I rocked from side to side, chanting the rhyming words, and Ian joined in again, smiling.

The third picture was of the moon. I wrote ‘fork’, ‘sit’ and ‘spoon’. I watched Ian closely without assisting him in any way at all, and could *see* him sounding out the words in his head. Without any doubt in his mind, he said “Spoon!” clearly and determinedly. Gosh. Now I was excited. We swayed together, chanting the rhyming words, laughing at each other. *

For ‘queen’ he picked out ‘green’ with no hesitation; for ‘cat’, ‘hat’; for ‘door’, ‘four’; for ‘bear’, ‘hair’; and for ‘fox’, ‘socks’. I was particularly excited that I wasn’t always writing words with similar spellings, so Ian was obviously working on the *sound of the word*, not his mental image of the word.

That was new task number one. It seemed to be on its way to being conquered, and with such good humour!

Then I decided to capitalise on one of Ian’s video soundtracks, preparing sheets for him on the computer, writing “A is for ___________” and following that with several blank lines for writing, then “B is for __________” with more lines. The second page had C and D, the third page E, F and G. **

I put the first page in front of Ian and said “A is for?” to which he immediately responded “Acrobat”, straight out of the Spot video. I let him write it on the line. Then I wrote ‘apple’ next to it. I pointed to the next blank line and repeated, “A is for…” and let him think about it. After a short pause, he said ‘animal’, and wrote down the word. I countered with ‘and’ and after a pause, he wrote ‘ant’. I wrote ‘as’ and he wrote ‘an’. I wrote ‘at’ and he thought for a moment and then, with a peculiar determination, said ‘a’ and wrote it!

For B, he immediately wrote ‘ball’ from Spot. I wrote ‘balloon’, he wrote ‘beach’; I wrote ‘but’, he wrote ‘bed’, I wrote ‘blow’, he wrote ‘bubbles’, I wrote ‘bear’, he wrote ‘bee’. This was getting interesting.

C became ‘car’ from him, ‘chair’ from me, ‘cards’ from him, ‘cat’ from me, ‘country’ from him (I didn’t even know he knew that word!), ‘candle’ from me and ‘cake’ from Ian.

D got even more interesting, with ‘drinking’ and ‘dear’ from Ian. Under E, he included ‘elephant’ (from Spot), ‘egg’ and ‘eating’. Under F, we had ‘flamingo’ from Ian, ‘Friday’ from me, ‘friend’ from Ian (clever boy), ‘farm’ from me, ‘far’ from Ian (oh, very clever, to just take off one letter!), ‘frog’ from me, ‘for’ from him, ‘flower’ from me and ‘from’ from Ian.

Under G, the last page I had prepared, Ian gave me ‘giraffe’, ‘goat’, ‘glass’ and ‘good’. I was impressed. Not only did I have Ian’s full attention during this task, he really applied himself to the problem of finding words starting with the requisite letter. It was marvellous to see him concentrating – you could almost hear the cogs turning!

If words are Ian’s strengths, I was definitely teaching to them. The most bizarre thing about how wonderful those two days were was that the previous day had been the most abysmal lesson we had quite possibly ever had. I was exhausted afterwards. And then such an overnight success. Quite extraordinary. I was a very happy bunny.

At the beginning of December that year I wrote to Kirsty –

“And what of our Ian? Well, he turned 11 the week before last, and seems to have grown each time I see him. He’s doing well in school at the moment, seeming to find great delight in reading and learning new words. We’ve started reading one of my favourite recent purchases, a children’s book called “Kiss the Cow”, all about a magic cow who gives masses of milk, but only if you kiss her on the end of her nose after milking her. A girl named Annalisa milks the cow but refuses to kiss her nose, saying “Ughhh! Imagine kissing a cow,” whereupon the magic cow stops giving milk and everyone goes hungry.

There are 19 pages in the book, so it's going to take us a while to get through the whole thing, but Ian happily reads pages 1, 2 and 3 now, and has learned loads of new words. He loves the name Annalisa, and the name of the cow (Luella), putting a musical lilt into the names which is hugely entertaining. He was also deeply self-satisfied when he could finally read the word 'prairie' – I whooped and cheered, and we shared a special moment, Ian wearing one of the little smiles he sports when he knows he's done something really clever.

The story starts so beautifully – "Mama May lived where the earth met the sky, and her house was as wide as the prairie. It needed to be. Mama May had so many children she couldn't count them all." (Ian can read all of this.) But the pictures are beautiful – the reason why I bought the book – and the story is delightful. Teaching Ian to say "Ughhh!" (Annalisa's reaction when asked to kiss the cow) is also great fun."

In the meantime, I ploughed on in my commitment to my child's education and continued to make sure he learnt something new almost every day, even if it was just one word, or that he took less time than the previous day to answer a question. When we went out together, I made Ian read the various signs we saw in shops or, on one occasion, at the train station.

"What does this sign say, Ian?"

"Please wait here," he answered.

"So that means we must wait here," I told him, as we stood in one place for a while 'waiting'. And so he learned that the signs around him had to be read and responded to.

I'm sure it wasn't really the kind of education the State had in mind for my child, but I believed it was important to my child's future, nonetheless.

Around this time, Kirsty had also asked me about my feelings on being both mother and teacher. This was obviously something I had thought about a great deal. She had suggested that doing both made you ‘face up’ to the autism in a way which someone who was tutor but not mother, or mother but not tutor, would not understand.

In reply I wrote –

“But does it make you face up to the autism? Hmmm. That comment made me stop and think. Yes, it makes you face up to it (in a working at the coal-face kind of way), but it doesn’t make it any easier to accept it. They’re not the same thing. I still struggle to deal with Ian’s autism on a daily basis. That never goes away. And the future is such a scary place when you have a child like this, an abyss one daren’t really look into because the fear is too all-encompassing. That awful “Should anything happen to us, what happens to Ian?” THAT is the worst of it.”

All in all, though, things with Ian seemed to be going well. He was participating in classes, laughing and learning, and we looked set to enjoy many more good months of hard work. It wasn’t always marvellous and there were days when Ian was just horrid, but mostly he was paying attention and classes had some element of fun to them.

Until one particular Wednesday…

Blimey! He was awful. I knew that we had good days and bad days, but sometimes there were days when I sat and looked at Ian and had to consciously work at not running away, hiding in the hills and leaving him to it.

I had presented him with our last task of the morning, a fairly new exercise, which required Ian to remember and write down what he had been doing in school. Ian sat and looked at the worksheet as if he had never seen one before. After having tried to chivvy him into giving me some sort of answer, and fast running out of 'I'm-an-unremittingly-cheerful-person' tricks, I leaned back and muttered quietly to the gods, 'Not a bloody thing'.

Leaning forward again, calm and determined, I asked Ian, "What did you do in school today?", and he picked up the pencil and carefully wrote 'Nothing'.

Okay, that was something anyway.

I pushed him to write on the second line and he grudgingly wrote 'reading', and then skipped a line and wrote 'nothings' and then went back a line and slowly and determinedly wrote 'No'.

Well, that just about summed up our morning!

Later Neil phoned me and asked how things were going, and I said, "Please come home. Ian's being awful and I want to run away."

He caught the two o'clock bus and when he got home he gave me a big hug, and sent me to my parents' house next door for tea and a chat.

Then January happened…

* * *

* Rudolph Steiner education – physical activity with learning enhances learning.

If anyone is interested in knowing more about Rudolph Steiner’s ethos, perhaps read – https://en.wikipedia.org/wiki/Waldorf_education

Also this – https://www.studyinternational.com/news/physical-activity-lessons-boosts-learning-schools/ (I love the idea of a ‘new study’ of something Rudolph Steiner knew a century ago)

** This ties in with the video footage I posted – Chapter Eighteen Extras

Chapter Twenty-Three

This is a particularly difficult period of time for me to write about. It seemed that everything I had worked so hard to achieve with Ian came crashing down all at once, leaving me feeling so utterly defeated I didn't know how I would ever be able to continue.

On the 28th of January 2007, I wrote a desperate email to my friends, Kirsty, Ruth, and another speech therapist friend, Deborah –

"How quickly things can change.

"No sooner were we commenting on the incessant wind affecting Ian's auditory processing than the wind dropped, the sun shone again, and Ian's behaviour took the most unexpected and violent turn for the worse.

"On Monday afternoon when Neil phoned me from work, I broke the news that Ian had spent one whole hour of that morning screaming at me, then he'd spent the next hour trying to hurt me, either with his head or his hands.

“In between screaming bouts and having to hold his hands down and avoid his falling head (which he aimed at my wrists – ouch!), Ian answered my questions promptly and accurately, and completed his worksheets well, even though his writing wasn’t quite as steady as usual. At the end of the most difficult morning we’ve ever spent together, Ian’s work record was a completely inaccurate reflection of his behaviour. My shoulder was stinging from the couple of times I wasn’t quite quick enough and Ian smacked my bare skin with his pencil, and my ears were ringing from his glass-shattering screams.

“Tuesday was not quite a repeat performance because I altered various things to avoid the usual pattern, but work wasn’t really on the agenda.

“On Wednesday we went out. Thankfully Ian was his usual well-behaved self in public.

“On Thursday, Neil was at home. He wasn’t feeling well and had decided that missing a moderately busy day at work by resting in bed would leave him strong enough to deal with Friday, a very busy and unmissable day. Halfway through the morning he came through to the kitchen and stood at the door watching Ian yelling at me, as he had for the past hour.

“Do you need some help?” he asked.

“Probably,” I smiled ruefully.

Interestingly, after Ian realised that his Dad was home, he stopped trying to hit me and I could finally let go of his wrists.

We battled through another hour with some almost pleasant, quiet moments – shattered by Ian’s screams the minute I opened my mouth to speak.

On Friday, we sat together in the lounge, just mother and son. Instead of asking him to read to me, I read to him, and he sat in my lap with my arms around him. It was a welcome relief just to be friends.

It’s strange how you find something in yourself you didn’t know you had. Last week I found a calm, quiet place deep inside me where nothing Ian did could touch me. I wasn’t affected by his noise, nor by his repeated attempts to catch me unawares with a hand-flick or a head-butt. My voice was soft and serene, and my composure couldn’t be rattled for as long as I wanted to sit and try to work with my child.

After those difficult mornings, I led Ian to his bedroom, quietly shut his door, and wandered through to our lounge to sit for a long, long time simply staring at our beautiful view, trying to work out what had happened to the gentle, loving, happy child Ian used to be.

Do I need help, Neil asked me. Oh boy, do I ever! The eleven-year-old autistic child is a force to be reckoned with, and I'm all reckoned out. I don't have any answers to the million questions I've asked myself, but I do know that for Ian there has to be a time when education must take a back seat and just being a person, trying to keep a grip on his world, must be more important. Perhaps he has learned all he can for now and needs time to just be.

That's all I wanted to say."

The responses I received from my friends deserve to be included almost in their entirety because they were so beautifully written, so concerned, so wholly supportive, and so very interesting. From Kirsty –

"Dear, dear Fiona

How I wish I was there!! Just to give you a hug, make you a cup of tea and lavish support. Because you do sound so alone. And I understand that calm, quiet place deep inside where nothing Ian does can touch you, but I also know it's a defence mechanism, and, though this may be hard to hear, it is ABUSE, albeit from someone who has a condition and has little other forms of power and control, and it will have the same effect on you as if anyone else you loved was trying to hit, head-butt and *hurt you. I once worked with an eleven-year-old (til she was thirteen) who used to bite and pinch me when she got mad, and sometimes for no reason at all. I took it and took it and took it and took it. I developed that "calm, quiet place deep inside" where nothing could touch me. What was the result over time? Deep, dark depression that took me years to get over. And a willingness to let other children abuse me, again and again. It's not right. And it's not right to take it.*

My instinctive advice to you is this: stop working with him. Take him for long, long walks instead, for a week at least. Show no interest in work at all. Give yourself a rest. If he tries to hurt you, walk out the room, go and do something else, give him no response at all. Don't stay there and take it, with the excuse that he's autistic. Please, please don't, Fiona, and I almost have tears in my eyes when I write this. Please don't take it, please don't allow anyone to do that to you, even Ian. You don't deserve it. It will erode you.

I send you a big big hug. I wish I was there to help you too. Please write and let me know how it goes."

From my friend Deborah, I received –

"I love this e-mail you sent because I can relate to it so much and feel a deep empathy and understanding and knowing.

In my work with autism, I have known many children to go through these extreme behavioural patches. I, too, have spent hours trying to work out why, wondering if it was something I did differently in the therapy session or what it was that set off a sudden outburst or difficult period. Sometimes I find out and sometimes I don't. It can be something in the environment but I do believe it can also be physiological – ups and downs, hormonal changes, emotional development, etc.

Children with autism have delayed emotional development and sometimes extreme behaviour at a later stage is due to this. Sometimes there is something physiological or sensory going on, sometimes it is something in the environment and sometimes we don't know what it is!

Mostly these phases just pass and things are easier again.
Courage and strength to you."

Ruth's initial reply was short and typically Ruth –

"My dear Fiona, Bloody hell … I'm SO sorry."

I sent Ruth a copy of Kirsty's wonderful email to me, and after she'd read it, Ruth wrote at length about her thoughts and feelings –

"Abuse? Yes. Depression as a result? Yes. Add to this an enormous dollop of guilt because 'why would a child (however 'dis-ordered') hurt me unless it was, in some way, MY FAULT? So while Kirsty has experienced the depression, I experienced more along the guilt lines from interacting with Ian and many others (even though Ian never hurt me, I was consumed with guilt that I couldn't just magically 'produce' speech FROM him – and FOR you). Whether guilt or depression, what is common, however, is the fundamental negativity of our responses.

So look at what you are DOING, Fiona – and see how instinctively you are returning to wonderful, positive interpretations of reality; walking with Ian for example – my goodness, how I remember Ian on our walks; how PERFECT our relationship was; how happy we both were. Instinctively, you know what to do to restore joy and balance in your lives. I guess my question is, why you would not think that working hard with Ian at 'making you both happy' is not an incredibly valid educational outcome – at least for now? Why not give yourselves the permission to work on this particular outcome and not to construct a time in your mind where you need to return to 'table work?'"

Ruth's reply to me led me to write a long and complicated email to her in which I expressed thoughts that had been plaguing me for months –

"Yes, when things go wrong with Ian I take it very personally, but I've learnt over the years (and remember, I've been working with him on and off for more than eight years now) that his behaviour cannot always be my fault. I have reviewed my own teaching style so often, I've been in danger of becoming as meaningful as a small puddle of water and sometimes I just have to get on with it. You did what you had to do with Ian, you believed in yourself, and you made him talk. I still believe to this day that if it hadn't been for you he wouldn't talk at all. So quit the guilt-trip, I'm not buying.

Many years ago (gosh, I remember it so clearly it could have been yesterday), you asked me "Do you want Ian to change or do you want him to be happy?" and these words have stayed with me ever since. You were absolutely right, you know. It's really hard to keep them happy while you're trying to help them fit into your world. It just doesn't work that way, not in the long run anyway. But it certainly doesn't pay to be negative about it. That way lies madness.

My latest malady – for want of a better way of putting it – is the end result of all this schooling. Here we are in Ireland, where the State is doing its best to ensure that these autistic children get some form of education – they're even being fussy about the kind of education they're getting (as if they have some Master Plan) and who they're getting it from (I've been told I'm not an appropriate teacher for Ian because I hold no formal qualifications), and I'm sitting here saying To what end? To what end all this education? Could we be preparing these children for a future that doesn't actually exist? And isn't that the unkindest thing we could possibly do?"

I found myself chasing my tail at this time, worrying about how to teach Ian this and how to approach that without Ian launching himself at me. I was tying myself into a knot with concern about all the things I felt he still had to learn, repeating the words, "I have to teach him … I have to teach him …" and then Neil looked at me with his beautiful, calm eyes and asked me one simple question:

"Why?"

I was halted in my tracks.

"Because," I countered, "because…" and then I realised I didn't know what the 'because' was.

In his gentle voice, my husband continued, "Surely keeping Ian happy is more important right now?"

And I knew he was right.

So school was abandoned. We went for long walks together and Ian was finding pleasure in his books again. I had temporarily disconnected his computer because he had been refining his computer pictures down to one single image, which he reproduced over and over again, and this image seemed to make him angry. When he asked for the computer I told him firmly, “No computer, Ian. It’s broken.”

And how was Ian through all of this recovery period? Well, it was a little like walking on eggshells for a while. Some days he was angry and noisy, others angry and quiet, and on other days he was good, sometimes even loud but happy, which was a great improvement. Occasionally he smiled too, which was wonderful. Things seemed to be improving. We had some great walks, even though the weather was still cold. However, it was dry and walking our country roads was very pleasant indeed.

Slowly, things settled down.

Ian was still hugely resistant to formal schooling when I dared to try it again but I had other tricks up my sleeve and managed to teach him new things without him even realising he was being taught. We started painting together, too, and I re-introduced him to the idea of modelling with play dough. We walked the neighbourhood flat, which was good for us both, and Ian seemed to enjoy being out and about so much.

He remained exceptionally well behaved when out in public – enough to convince me that his resistance was aimed solely at me – which meant that we could still do the shopping together with no trouble at all. I had always believed that how Ian behaved in public was as important a part of his education as how or what he learned in school, and I was grateful that this part of him had not changed.

* * *

Chapter Twenty-Four

It is many years since Ian was diagnosed, and so, after all this time, how does it feel to have an autistic child?

Well, there’s the social version that insists that you love him just as he is, wouldn’t change him for the world. And you smile as you say it and try not to look too brittle. But inside lurks the real, secret truth, which knows you’d change him in a heartbeat if you were given half a chance.

Having an autistic child feels … like having been wounded deep inside, like having been assaulted … *violated …* by nature. You can live with it, deal with it, even accept it to a certain degree, but there’s a hurt inside that never goes away.

The evenings are the worst, when the stresses of the day sit, accumulated and hanging around my neck. When bathing a growing child for the umpteenth time just stretches into endless future baths. When I can see myself, older, less strong and fit, still supervising the adult, the man, naked in front of me, still needing prompting to wash ‘those important little places’ as my Mum used to call them, still chatting to himself and not to me. Still relying on me absolutely, because in my mind’s eye I cannot see it any other way, no matter the hours of work I’ve put in teaching him to be independent.

And then that silent howl rises up from deep within and the tears stream, and I try to hide them because I don’t want to upset my child, but a gentle hand reaches out to touch the tears and a husky little voice says “Sad”.

It isn’t a question, merely a statement of fact. Tears equals sad. He’s learnt this.

Sometimes there’s concern behind it; mostly there isn’t.

The silent howl goes on, but somehow I control it and respond, “Yes, my boy, tonight mummy’s sad. Let’s have hugs”.

And I hold him close because he’ll let me, and I breathe in the scent of his hair, and remember the little angel sent from heaven just for me, and I cry.

But I carry on.

Is it self-pity? Loss? Despair? I don’t know. I’ve examined this wound from so many angles I’ve lost count, and even today I can’t say why it remains so fresh, as if yesterday was the day on which we were told our child was different, not some sunny afternoon so many years ago.

But there’s the good side, too. The little reminders of what a special child Ian is, when he takes my hand for no reason other than that I’m nearby, or when he climbs into my lap for hugs just because I’m sitting down.

Or like the time he rushes into the kitchen, looks me straight in the eye and says “Mummy, come …” and I follow him to his bedroom where he’s been typing on his computer and he points to the words and tries to read what he’s typed, and I correct a rare spelling mistake, and such a happy smile spreads across his face because now he can see that it’s *right*, and he *understands* that it’s right, and he reads it again, because he can.

Mostly these days I am swamped by thoughts of all the things Ian can't or won't do, and all the things he still ought to learn; but if I manage to take a step back, I look at my strange, self-contained son and think how good he is, really. Okay, he doesn't share much of himself, he doesn't share his thoughts or his feelings, but he can express himself well enough. He can ask for what he wants or needs. He can make his displeasure known in words if he feels like it, and he can do many things for himself, too, these days. He has finally accepted that getting dressed in the morning is just another part of daily living. He chooses and carries books to the car to keep himself occupied on a journey. He clears his place at table after a meal. He still behaves impeccably when we go out together and is a quiet, well-behaved companion when we go shopping, pushing the trolley for me, reading my shopping list, finding the right aisle by reading the overhead signs, and taking correct items off the shelf. Quietly, he is using more language, more appropriately, to express himself.

Ian will always need supervision and help, and will always require guidance for so many things. Full independence was our original goal but the arrow fell far short of our aim. He still has a lot of growing up to do, and there's no way of knowing where Ian's behaviour and abilities will finally settle. We remain optimistic. We still love him to distraction and will continue to protect him from the world for as long as we can.

Despite everything, all the ups and the downs, all the stress and the angst and the suffering and the soul-searching, Ian has always been – and *will always be*– my little angel sent from heaven … just for me.

Epilogue

I finished writing this book several years ago, and many things have changed since then.

After that disastrous January when our home-schooling programme fell apart, we coasted for many months. Ian spent his days at home with me and we passed our time together walking, shopping, going to cafés for tea, watching TV, reading, playing computer games, listening to music, and laughing. But of school there was none. Not in any formal sense. Ian learned quietly, obliquely almost, about life and his place in it. I continued to expand his word skills and did my best to keep him happy whilst at the same time keeping him awake, *there,* present and consciously participating. It was pleasant and comfortable for both of us.

And then a good friend who has a special needs child of her own sat me down and told me quite plainly that Ian needed more. Most importantly, he needed to learn to deal with his peers. Neil and I would not always be there, she said, and Ian had to be equipped to deal with a life filled with 'his' kind; he had to be able to deal *now* with a life beyond us. She apologised for being blunt, and I'm sure at the time I was disturbingly quiet and withdrawn, but only because I knew she was right. Ian had to go back to school.

So, we enrolled him in a Special School which had a class devoted to autistic children. It was a good place, welcoming and friendly, and the headmistress and staff were lovely people. But of course it fulfilled my deepest fears, didn't it? What kind of example would be set for Ian when he spent every day faced with – and imitating – the behaviours of people like him, when that very behaviour was something we had worked so hard to modify? Confronted by the prospect of that, my heart was breaking.

On the other hand, for the first time in many years, I was *free.*
Yes, when the holidays were over and Ian went back to school, I did my little 'Braveheart' dance around the house, crying "Freedom!" to the silence. It was glorious, and I loved it. My time was my own.

What I had to learn to live with, though, was the guilt.

Guilt because I felt I'd failed him. Guilt, because for me, this was the easy option. Guilt even because I feared I wasn't strong enough or brave enough to continue working with him myself, as I wanted to, because I believed it was the right thing *for him*.

* * *

Ian has been at school for several years now. He has grown up and become a man. He is so different from the little lad he used to be, it's easy to forget. Now, children stare at him in the supermarket with a deep intensity, aware of his strangeness and unsure whether he's to be trusted or feared. I see this and my heart is squeezed. He's tall now and he remains strange. I'm not surprised they stare. How could they know my angel has a gentle soul and wouldn't hurt a fly?

On the whole, Ian has coped well with school and participates in the many activities provided there. He enjoys his cookery and woodwork classes, and looks forward to being allowed to play on the school piano or the school computer. He isn't pushed in any meaningful way, and because of this, of course he has regressed. He has withdrawn into his autistic self to a very large degree and although he can be drawn out easily enough, he's a shadow of the bright child he used to be.

I remember how happy Ian was in his mainstream kindergarten class so many years ago, mixing with typical children of a younger age. How forgiving they were towards him, not yet fixed in their attitudes as to what behaviour should or shouldn't be. How lucky we were to have experienced those few precious months in that beautiful environment, where Ian was growing and absorbing all that was good. What could have been achieved, I wonder now, if it had been possible for that to continue?

We will never know. Today, Ian is 18. He remains profoundly autistic. *And yet*… all the things he can do – his speech, his computer skills, his extraordinary and wonderful abilities – are ALL there because of the hundreds of hours the therapy team and I spent working with him, all those years ago.

Was it all worth it? Without hesitation, I can say it most definitely was.

Would I do it again? In a heartbeat.

Ruth was right all those years ago. The little shit *was* clever. He still is.

He's an amazing young man.

The End