

'When Horse Became Saw'

This extract comes from a book-length work of creative non-fiction that documents my son's regression into severe autism at the age of eighteen months, and my family's struggle to provide him with appropriate therapy. The book will be published by Penguin Australia in March 2011. It was funded by two New Work grants from the Literature Board of the Australia Council (2006, 2008), as well as an Early Research Project Grant from UTS, and a Faculty Project Grant from UOW. This 2008 Meanjin extract received enthusiastic media attention in a review in the Age newspaper (13/08/2008), and in an ABC Radio broadcast (2/08/09).

The extract depicts the initial stages of my son's regression, which lays the foundation for the book's structure. This comprises both narrative and researched components, and applies an innovative methodology to the creative non-fiction genre: the bodies of knowledge required to understand and treat autism as well as a critical appraisal of them become part of the lived experience dramatised in the narrative. The research underpinning the extract is extensive, and falls into two areas. The first is the investigation of clinical matters: aetiologies and definitions of autism (DSM-IV); the history of behaviourism (Skinner) and the autism-specific therapy Applied Behavioural Analysis (Lovaas). The second deals with social and ethical issues, and investigates inadequate public resourcing and its consequences for children with autism and their families.



WHEN HORSE BECAME SAW

ANTHONY MACRIS DESCRIBES THE EXPERIENCE OF DISCOVERING THAT HIS SON HAS AUTISM

ALEX STOOD IN THE MIDDLE OF THE LIVING ROOM, his toddler's small fingers firmly wedged around the stomach of a toy lobster half his size, its soft, transparent plastic an iridescent orange. As he squeezed the stomach its large claws, weighed down with last night's bathwater, swayed somewhat menacingly, but he took no notice; he was intent on getting it to squeak. Despite his best efforts, it refused: the squeaker had gone silent. He looked over at us, clearly frustrated, and clearly wanting us to do something about it.

Kathy and I were, or course, fiercely proud of him, and reserved the right of all parents, and especially first-time parents, to claim that he was the most beautiful, intelligent and vibrant child in the world.

Development: raising a child was all about development. Gross motor, fine motor, sensory, cognitive, social and emotional: these terms flooded into our lives moments after our first son, Alex, was born, and they fascinated me. A budding human being was a creature teeming with life, with potential. There was so much to nurture, to foster, so much satisfaction to be gained from watching Alex grow and evolve. Yet even if a human being was programmed to develop, this didn't necessarily mean they would. They needed the right conditions. They needed loving parents, stability; they needed a watchful eye, a firm hand when required, or a delicate touch. This was where the challenge and achievement lay: in taking responsibility for the creation of a happy, capable, useful human being. And this was where I felt I was doing something more important and rewarding than I had ever done before.

It's one thing to fully embrace the responsibility of raising a child, but it's quite another to pull it off. As a first-time father I was full of enthusiasm, but without any experience. Kathy, as the eldest of seven brothers and sisters, knew a lot more, but there were things she couldn't quite remember. A major source of help came in the form of one of those parenting guides the size of a house-brick that fill our major bookstores. We'd been prompted to buy one after Kathy and I had had a disagreement over some matter that had escalated into an argument way out of proportion to the problem itself, and which had largely been created by our unwillingness to admit we didn't really know the answer. The book soon became a useful tool that took the sting out of many of our disputes, and turned them into discussions. How long should a baby sleep at six months, at nine months, at twelve months? I had no idea, and Kathy wasn't sure. How high should we let a fever go before taking him to the doctor? We didn't have a clue. The Baby Bible, as it came to be known, gave us basic information we could work with.

It also contained the lists of milestones, the things your child should be doing at any given age. In the evening after dinnertime, Kathy and I would sit on the sofa,

Alex nestled between us, and go through the lists. At twelve months could your child 'cruise'? Cruise? He had already been walking for three months! Could he use his fingers in pincer movement? Alex could remove the tiniest sultana from his cereal with the most dextrous fine-motor movement imaginable. Did he understand, and use, the word 'no'? Of course he could. The very questions were an insult! List after list, at twelve months, at fifteen months, it was clear he was above average. How many words did he have? This would regularly end up in a debate between Kathy and myself. It was clear he had 50 per cent more than the average, but this was not good enough for me. Surely there were more? I'd elicit words I thought he might be able to form, and count them: close enough was good enough. Why couldn't we count 'kah' as computer? Kathy was somewhat more realistic in her estimates, and was also keen to put a stop to what was becoming the kind of mixture of smugness we all know and find so insufferable in parents who think their child may be 'gifted'.

Alex grew, and every day Kathy and I loved him more. It was strange, this new love that seemed to have no limit. It was a love totally different to anything that we had experienced before, and required some recalibration of our feelings towards one another. Before Alex, we lived the cult of the couple, with all its emphasis on personal and mutual fulfilment. But we were no longer a dyad: now we were a collective, one of the smallest that could be imagined, true, but one that called for a whole new approach to our lives.

Once I realised I had these feelings, I was quite stunned by them. They represented a complete reversal of everything I had felt before. The cool rationality towards my most basic feelings that I prided myself on cultivating in my twenties and thirties evaporated. The love Alex had brought with him, this collective love that was very specifically situated in its own three-part system, was breaking me down, eroding my previous independence and individuality. It confused me, this new love that Alex had created. In any given week, on any given day, it scared me, sustained me, entrapped me and liberated me. But one thing at least was clear. I couldn't conceive of life without Alex. If anything were to happen to him, if he were no longer to exist, my life would be unrecognisable to me.

When Alex was around sixteen months old he was given a large, purple plastic crocodile with a xylophone embedded in its back. One mid-afternoon I unwrapped it for him in his bedroom.

The instruction leaflet included a diagram to assist small children and musically illiterate adults (I was one of them) to play 'Twinkle Twinkle Little Star'. It was a song Alex knew well and, following the colour chart, I banged out a passable version for his benefit. Alex listened to a couple of notes, giggled distractedly, then twirled in a circle. This behaviour had been creeping in for some time, but it was not yet consistent. And on this occasion, as on others, I put it down to tiredness: after all, it would be time for his afternoon nap soon. But then he did something that disturbed me. His gaze still somewhere else entirely, he twirled around, picked up the crocodile and, for no apparent reason, hurled it into space. It hit the wall, tearing the wallpaper and dislodging a small piece of plaster. Throwing a toy is something any young child might have done. But there was something very odd about the way Alex did it, and I was too surprised to admonish him. It was as if he did not recognise that it was a toy at all. The object seemed to puzzle him. What was it for?

It made noise. Why did it make noise? What was the noise for? The throwing of it seemed a reaction to this incomprehension, an underlying frustration.

But if he was frustrated, it was only momentarily. I looked over at him to where he was sitting on his bed, flicking through a Winnie the Pooh book. The crocodile seemed to have passed in and out of his world in a split second, utterly forgotten where it lay on its side in the corner, its jaws wide open. It was as if it had never existed.

I sat next to him and asked him to pick up the crocodile and put it away. He didn't even look up at me. His gaze was fixed on an illustration of Winnie the Pooh's backside, the rest of him stuck in a honey jar. I asked him again, somewhat sharply.

'Alex, get up, please, and put the crocodile in your toy box.'

At the sound of his name he looked up at me. But his gaze seemed to skitter across mine, as if he wanted to avoid the moment of direct eye contact at all costs, as if it were somehow too much for him.

I picked up the crocodile, put it in the box and left the room.

It was a couple of days later, a Saturday night, and Kathy and I were on the sofa watching television, the volume turned down low. We had put Alex to bed ten minutes earlier, but we knew he wasn't asleep; we could hear him twisting and turning. A thump on the carpet, the scuffing of feet. Wearing only a singlet and a nappy, Alex shuffled into the living room, his eyes pink-rimmed and his face a little puffy. He was smiling and I noticed that his smile was strangely blank, glazed and intense. People can often look very different when they're emerging from deep sleep, and there's always a small shock that comes with seeing the recognisable altered in any way, no matter how fleeting. But this was different. There was a disturbing edge to his smile, as if he had become altered from within.

His behaviour became stranger still. He came to a dead standstill in the middle of the room, then planted his feet on the floor. He paused for a split second, the kind of pause that occurred before a sneeze. Suddenly, he raised himself up on his toes as if some outside force were lifting him. And then it hit him. A wave of sensation coursed through his entire body, a wave that completely exhilarated him. His small limbs trembled with excitement, his face lit up in an expression that verged on the ecstatic, he made whooping noises of nearly uncontrolled delight. He giggled and resumed his toe walk for a little while. And then it was all over. The curiously blank enigmatic smile returned for a while, then lapsed into a glazed torpor. He yawned. He was very tired.

It was at this point that there was a shift in my degree of worry. My suspicion turned to something much more unsettling, something much more concrete. Only later would I realise that it was fear, the deepest fear I had ever known. It tiptoed to the edge of my conscious mind and sat there, watching, waiting for my concerns to be either proved or disproved.

Kathy, too, sitting next to me on the sofa, had witnessed this spectacle of Alex's ecstatic transport. I could sense her worry, but, as if by some tacit agreement, neither of us said anything. Later we would call these spasms of sensation the sea anemone, because it was like watching one of those other-worldly sea creatures have its entire body animated by the current that supported it, totally at one with its environment, with no separation between it and the world.

Soon after this incident, it became apparent that something strange was hap-

pening to Alex's language. I was on the way to visiting a friend who had a young son around Alex's age. We didn't have a car, so I was pushing the stroller to the train station. It was a hard job. The Ashfield footpaths around where we lived were narrow and not particularly stroller-friendly, and Alex was big for his age; he was tall, slim and strong, a beautiful boy. He was not helping matters by perching himself on the very rim of the front seat and dragging the sole of his sandal on the front wheel. To distract him, I played one of our word games. It was a simple question-response game, based on his favourite animal book.

'The lion goes . . . ?'

'Raar!'

'The sheep goes . . . ?'

'Baah!'

'The monkey goes . . . ?'

'Baah!'

I was a bit surprised. He knew very well the monkey went 'eep'. He usually didn't make that sort of mistake. I tried an easy one.

'The cat goes . . . '

A pause. 'Baah!'

We caught the train over to the city and walked to a park in Darlinghurst where we were to meet my friend, Paul, and his eldest son Roy. Paul was an HSC English teacher who had taken a year's leave to look after his two boys. We had met ten years earlier, and had been good friends ever since. The park wasn't large, and I spotted Paul and Roy immediately. Roy was balanced on Paul's hip, whispering in his father's ear. I immediately noticed that he was producing what seemed like parts of whole sentences. I hadn't seen Paul or Roy for a few weeks, so this development seemed all the more impressive for its suddenness. Roy was only a couple of months older than Alex, but Alex didn't seem to be at anything like that level. I didn't mention anything, but I was completely spooked.

Throughout the afternoon Alex did not take much notice of Roy, even though Roy would try to engage him. At one point he ran up to Alex to play chasings, but Alex only responded with a kind of nervous indifference; he turned away and went off to a quiet corner of the playground where he could be on his own. Roy was visibly disappointed. When it was time to go I went to get Alex. He had spent most of his time in that same corner. I found him spinning round and round, his faced fixed in a beaming smile. I put my arm on his shoulder to still him. He looked startled, like someone woken from a trance.

On the train home, I felt very uneasy. Alex knelt on the side bench, staring out the window at the passing terrace houses. It was like a depth charge, this kind of worry: it released itself like a muffled explosion somewhere deep inside you, and only surfaced much later. I thought back to the moment, a couple of hours ago, of first seeing Roy speaking to his father. He had spoken in a soft voice into his father's ear. I hadn't been able to make out what he said; all I could make out were snatches of whispers, hushed and secretive because of the presence of someone else. But, on reflection, what struck me more was the expression on Paul's face. It seemed to be lit up by these exchanges, so new, so thrilling; the speech of his son full of new meaning and complexity, the expression of his burgeoning personality made into words. It was as if Roy's speech had become light, a light that passed between them, that illuminated their minds and souls. And I was suddenly acutely aware

that I had not yet felt any such connection, such a delicious complicity, with Alex.

Well, Alex was standing right next to me. I could test it out. I turned him away from the window. He was reluctant to leave the view, but did. I stood him up so I could talk closely into his ear. I said, 'So, my little man, you like looking at the houses?' He giggled at my breath on his ear, then squirmed to turn back and look at the passing view.

My little test had failed. It agitated me so much that I nearly missed our stop.

Physically, Alex continued to thrive. He was a little Adonis with his soft golden curls and his slim, sturdy frame. A few weeks after the visit to the park with Paul, Kathy and I were sitting with him in the lounge room, his Lego set spread out before him. It seemed to confound him. When we tried to show him how to join and stack them, he appeared to be at a complete loss. His fine motor movements, so precise whenever he wanted to remove a bit of unwanted food from his bowl, became awkward and tentative when he had to consciously perform some logical task. Kathy suggested we scale back to a simpler toy we had put away because he had mastered it, a set of small multicoloured cups of diminishing size that could be stacked into one another, or also stacked on top of one another to build a tower. Crouched down on the floor with him, Kathy and I tried to help him build the tower. He seemed confused, and needed a lot of guiding just to select a tub. When he did finally get going, he got the sequence wrong, attempting to stack larger on smaller, or confusing the base and the lid. I finally did it for him. He sat and watched me do it and, with a casual wave of his arm, knocked it down. We sat there, all three of us, among the multicoloured rubble strewn across the floor.

'He could do this two weeks ago,' Kathy said, bewildered.

On a mid-summer evening, Kathy and I sat down with the list of 18-month milestones. This time, we opened the book somewhat nervously. Alex had not been talking much lately, barely producing a word, and had seemed prone to long bouts of being distracted and vague. We'd go to the park, and he'd come along happily enough, holding my hand as we went to the swing and did our routine half-hour. But not a sound came out of him, apart from a mixture of babble and jargon with only the occasional word. Also, he seemed to have stopped saying 'Daddy' in any shape or form. For quite a while it was clear he identified me as 'Dah', but now there was nothing. I found it deflating. Also, in certain places he seemed to totally zone out, as if he was either trying to block out an environment he didn't want to be in, or was somehow overwhelmed by it.

As Kathy and I sat down to go through the milestones, there was definitely no atmosphere of unbounded optimism. We worked through the lists. It soon became apparent he'd barely progressed since fifteen months. In fact, he'd gone backwards. A wave of guilt coursed through me, and in Kathy's silence I could feel it go through her too.

What on earth had we been doing? Why hadn't we said something?

But still I couldn't raise my concern that there may be something wrong with him.

'It's only a book,' I said. 'They're only averages.'

Strange how we believed everything the book said when it confirmed that he may have been 'advanced'.

Things started going wrong at child care. Alex had been attending the local centre for two short days a week since he was about eleven months old. The centre was well run and, apart from some very standard settling-in problems, we liked to think that he was happy there. But a month or so after we checked the 18 month milestones, things changed. Alex started to cry as we approached the centre, as opposed to crying simply when he was left. And when it was time to say goodbye, he became fearful and distressed and refused to go into the Twinkles room to join his group. The carers also informed us that he was difficult to pacify once either his mother or I had gone.

Over the next few weeks Alex's distress got progressively worse. His eye contact, now generally rare, was reserved for anguished, tearful looks as I said goodbye to him. Kathy said it was the same when she dropped him off. I began to dread the days it was my turn to take him, and when I got home I was so worried about him that I found it hard to get any writing done.

One afternoon Kathy got home with Alex, and immediately burst into tears. Alex had cried before she dropped him off, but with a degree of fear and anxiety she hadn't seen before. And the carers had told her that he had cried like that, on and off, for half the day. Perhaps they should have called us, but they felt it was a borderline case. When left to his own devices to see if he would calm himself down, Alex retreated to a quiet corner of the playground, and ran up and down. This seemed to pacify him. But they couldn't let him do that all day. They had been about to call one of us when Kathy turned up. He clung to her like a limpet for five minutes, and she had to prise him off.

We both stood in the kitchen, overcome by guilt. Alex sat on a kitchen chair and munched his sultanas from a box, his eyes puffy and swollen, his legs swaying back and forth. His gaze was remote and abstract.

Kathy made herself a cup of tea and sat at the table, staring into space. She was more upset than I had ever seen her before. I was suddenly terribly afraid for two of the people I loved most in the world. I said that I thought we should get Alex checked out. By a paediatrician. There may be something wrong with his development. I used the word 'development'. Not 'him'. 'Him' seemed too direct, too brutal.

Kathy sat at the kitchen table, the tea steaming before her. Her eyes were glassy with tears. She seemed numb. Finally, she nodded in agreement.

Over the next few weeks, Alex's decline became shockingly rapid. It was most noticeable in his language. Words fell away on what seemed a daily basis, and the ones he did still know started to deteriorate: they reversed, scrambled, reduced to a single ill-formed syllable before they too perished. We sat and went through a picture book. 'Flower' became 'walah'. 'Horse', which he could say clearly, became 'saw'.

Sometimes, when he tried to form a word, he added a syllable in what seemed like a struggle to keep saying what he knew. We were out on an evening walk, a mild Sydney evening with a dusty blue sky. Venus appeared, a spark of light. And Kathy asked: 'What is it, Alex? What is it?' pointing up to the horizon. There was a delay, a delay that had grown so incrementally that I barely noticed it. Alex's face was hesitant. He struggled to form the word, put an 'e' before 'star' in order to manage the 's', as if he were speaking in Spanish.

Soon the word 'star' disappeared. The amount of babble he produced increased,

the words getting lost in his attempts to form sounds, rather than emerging out of them. Within only a few weeks his remaining functional words were 'no', 'stuck' and 'Mummy'.

Then, finally, 'Mummy' underwent a grotesque reconfiguration. One night Alex stood at the door crying, his mother kneeling before him. She was primed and perfumed, ready to go on a girls' night out. Tonight it would just be me and Alex, the boys at home on their own. He was crying because he knew what was about to happen—the perfume, that extra-special goodbye, filled with its promise of a quick return—it meant mummy wouldn't be around for bedtime, and he got upset. He would settle down soon enough, and we would have a good night, but for the moment he was distraught. Kathy's face filled with concern; she said she should probably stay at home, stay with him, but I told her to leave, that I would handle it. It was easier said than done: after she had gone he continued to stand at the door, wailing. But tonight he wasn't saying 'Mummy'. It had become 'Um-ma', two fractured syllables, a pseudo-word he repeated over and over again with an insistence that unsettled me.

Within weeks 'Um-ma' was reduced to 'ma'. By this stage there was little left of Alex's language. All the words we had given him, the words from the books we got from the local library, from the boutique book stores, from remainder tables, the books given as gifts at birthday and Christmas, the words taught to him as he sat in our laps or snuggled against us at bedtime, all these words were vanishing. In what seemed like no time at all his vocabulary was reduced to the most basic, significant words, the words that designated the things that were most important to him. And then, one by one, those labels too were torn away, until Alex could no longer really say anything intelligible at all.

This period of onset happened so swiftly, with such irreversible force, with such absoluteness, that Kathy and I were stunned. In the days leading up to the doctors' appointments I had arranged, we operated in a kind of emotional vacuum. It was like something in a science-fiction film. The world seems utterly normal, but there is some alien force at work that is capable of penetrating an individual's nervous system and rewiring it, leaving them physically unchanged yet altered beyond recognition. Only it wasn't a film. It was happening to us. To our child. It seemed completely inconceivable. To our child? A child who had been wanted, planned for to the nth degree? A child born out of love? Could this happen to a child born out of love? Wouldn't that alien force know, know how much he meant to you, and leave your child alone?

One night, before it was time for Kathy and I to go to bed, I told her that I wasn't feeling all that tired, and that I was going to do a bit of web surfing: I'd be in soon. Kathy went to bed. I waited until I thought she was asleep before I logged on.

I entered the word 'autism' into the search engine.