

Whose story is it?

Rachel Robertson

I was going to be a novelist.

At the age of six, I was writing fiction about a willy-wagtail, whose best friend was an ant. (Even then I had a good grasp on relationships!) Several years later, I had moved to human protagonists—mainly young girls living in boarding schools and excelling at ballet. I had no experience of either boarding school or ballet but I had my dreams. By adolescence, I was writing fiction about homelessness and drug addiction—once again, from vicarious experience. And then I went to uni to do a literature degree and realised that great Australian novelists were serious, learned and (then) mostly male. I still wanted to write my novel, but I decided I had to live a bit first.

I did my living, and it was the experience of having a child that brought me back to writing again. When my son was diagnosed with autism at three years old, I started writing about my own life and his life. And I'm still doing that.

I could have written about parenting and autism in a novel, but I knew that wasn't what I wanted to do. I knew that this story, for me, could only be told in the form of a memoir—a form that combines notions of meditation, remembrance and mourning and which can hold even the most fragmented and chaotic life in its compass.

Like many parents, I recognise something in the ordinary, everyday experiences of parenting that I want to capture and share with others. I want to convey the extraordinary in the ordinary.

Not that my son is entirely ordinary. Once or twice, I've even wondered if I was impregnated by a creature from another planet. But I suppose I would have remembered that.

My son is eight now. His favourite foods are green apples and lettuce stalks. He loves numbers and Thomas the Tank Engine. He is funny and happy, confused and anxious. He likes repetition, predictability and order—in other words, life as it is not.

How hard it is to capture in words the essence of people you love.

But more difficult still is working out what you have the right to write about. It might seem okay for me to tell my story, but since a large part of my story is mothering my son, how much of his story can I tell? Whose story is it? Who owns the story of our relationship over time? How do I tell it truthfully? What *is* the truth of our relationship? Do I have the right to talk and write about my son as autistic or is this a form of labelling that he should have the choice to accept or reject himself? How will he feel when he is older if he reads what I've written?

These are just some of the many questions I have asked myself and continue to ask. And, as is my way, I went to women writers I admired and read what they had to say on the ethics of writing about others.

The novelist Lynn Freed is not reassuring. She argues that writers are natural murderers and moral reprobates. When faced with a choice between truth and decency, even the mildest of writers, she says, will choose truth: 'If it is done right, someone will be hurt.'¹

Helen Garner seems to struggle more with the dilemmas of writing about people in fiction and non-fiction. She says:

I thought I'd be ethically in the clear as long as I wrote 'in good faith'—that is, if I laid myself on the line as well, applied to myself the same degree of analysis and revelation that I did to the other people concerned. I still happen to think this attitude is legitimate as far as it goes—but it's based on an assumption of consciousness in the novelist which is over-optimistic to the point of being grandiose.²

I take her to mean here that we don't really know what we are doing as we write—that we write blind, that writing comes long before understanding. Nonetheless, it's an appealing idea that you are in the clear if your intentions are good and you expose yourself at least as much as you expose others.

However, writing about a child, especially one with a disability, is a bit different from writing about an adult. My son is what Professor Thomas Couser calls 'a vulnerable

subject'.³ For this reason, I need to be even more careful. The other side of this is that living with disability changes the level of privacy you can expect.

Before my son reached the age of four, I had breached his privacy many times. I have to tell my story to strangers all the time. What I am asked to tell as a parent is a particular type of story. The scaffolding for the story is provided by the context and the professional I am talking to. When my son was being diagnosed, I spent hours answering questions put to me by a developmental paediatrician, a psychologist and a speech pathologist. The paediatrician asked about developmental milestones and physical health. The psychologist was interested in play and relationships. The speech pathologist focused on language. All these separate stories came together only in me. I kept trying to return to my son as a whole person, but then I would get derailed into a detail, like the way he mixed up pronouns or what he did in noisy places. At the end of the process, the paediatrician wrote a five-page report on my son, indicating which of the criteria he met for a diagnosis of autism and why. Reading it was a strange experience. It was true but untrue. It seemed to be less a story about my son than about a boy who failed to do certain things that his mother and these professionals expected him to do. The woman in the story—that is, me—was also strange. The report was full of phrases like, 'the mother reports that' and 'according to the mother'. It was only on reading the report that I realised the extent to which I act as translator and mediator between my son and the rest of the world. Of course, all parents do this with young children, but I realised then the power that such a role carries when your child has a disability.

Over the years, I have briefed psychologists, speech pathologists, occupational therapists, therapy assistants, school teachers, education assistants, sports instructors, swimming teachers, hairdressers, dentists, neighbours and childcare providers. Every time I talk about my son, I am rehearsing his life story, choosing which things I need to say and which I leave out. I am exposing his challenges, his anxieties and preoccupations to a stranger, who will work with him for a while, but who usually moves on within less than a year. And each person takes notes. They have a file on my son at the school, the Disability Services office, the local council, the non-government agency that is supposed to provide services to the school, the respite service we never use, the childcare service he is too old to use, the doctor's surgery, the hospital, and at

the offices of all our private therapists and all the researchers who have asked us to participate in autism research. The purpose of giving information to professionals, schools and community organisations is to help them work more effectively with your child. That is totally benign. But how benign is it that little pieces of my son's life are lying around the city of Perth, out of our control, never retrievable? Who owns these stories? And how truthful are they?

In the end, I have decided that I can tell certain stories about my son and our life together. I want other people to read these stories, because I want them to know that 'a child with autism' is funny, interesting, loving and loveable. He is much more than just a list of challenges or deficits. My work is really a form of 'counter story'⁴—a way of talking about my son that accepts his disability but doesn't define him through it.

I try to be truthful in my work. If, as Drusilla Modjeska suggests, evidence and imagination vie for ascendancy in memoir, then I try to allow both their space. I like Modjeska's idea that memoir is 'a mapping of the mind' as well as the re-creation of experience, that what matters may not be 'truth to a narrative that exists outside the text' (because of course there isn't an outside narrative) but rather 'fidelity to the creative process'.⁵

A few months ago, my essay called 'Reaching one thousand' was published by the *Australian Book Review*. It's a series of reflections on my son's interest in numbers, the fact that both my parents were mathematicians and my own resistance to, even fear of, numbers and mathematics and how I have changed over the years through my experiences with my son. Of course, because I was writing about numbers and maths, I ended up writing about my parents and my siblings too. I didn't mean to—perhaps this is partly what fidelity to the creative process looks like. This was a challenge for my family and they responded with generosity and forbearance. But it taught me how hard it is to isolate my own life from other people's. How hard it is not to steal other people's stories and violate their privacy. It showed me through experience what life-writing theoretician Paul John Eakin claims: that ethics is 'the deep subject' of all autobiography.⁶

I don't have any answers to these ethical dilemmas. Writing about other people's lives is a bit like other forms of relationship with people: there are no rules, you do your best, you try to avoid harm, but sometimes you betray people.

Even my son struggles with notions of truth, self and reality in literature. He writes stories about two best friends, a frog and a toad. He often asks me, 'Is this a fiction or non-fiction story?' and sometimes I'm not sure what to answer because his stories are made up but also true. Although he writes and illustrates these frog and toad stories himself, he obviously sees them as shared works, because he asks me to act out the stories with him, allowing a certain amount of improvisation. As Toad (and I am always the toad), I get to make some changes to the storyline and dialogue, so long as I stay within his general conception of what Toad might say or do. Sometimes I stray too far from his truth and he tells me off: 'No, don't say that.' As with all collaborations, these stories change over time and according to the context. They may shift a little towards Toad's perspective or more towards Frog's and sometimes they even reflect a shared perspective, becoming both our stories. What is consistent in these stories is that Frog (my son) is the wise character and Toad (me) is the foolish, confused character, the one who learns. And this, of course, reflects a deep truth that all parents know: we learn more from our children than we teach them.

¹Notes

Lynn Freed, *Reading, Writing, and Leaving Home: Life on the page*. Orlando: Harcourt Inc., 2005, p. 38.

² Helen Garner, *True Stories*. Melbourne: Text Publishing, 1996, p. 6.

³ G. Thomas Couser, *Vulnerable Subjects: Ethics and life writing*. Ithaca: Cornell University Press, 2004.

⁴ Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair*. Ithaca: Cornell University Press, 2001.

⁵ Drusilla Modjeska, *Timepieces*. Sydney: Pan Macmillan, 2002, pp. 195–6.

⁶ Paul John Eakin (ed.), *The Ethics of Life Writing*. Ithaca: Cornell University Press, 2004.