Friday essay: on telling the stories of characters with Down syndrome

Sarah Kanake
Lecturer in Creative Writing, University of the Sunshine Coast

In 2014 I was asked, by my then university, to present in a jovial end of year debate. My partner, brother and a few of my close friends came to watch. The auditorium was packed. There were university bigwigs on both teams. I was pretty nervous. It went well, although many of the debaters thought they were presenting in a real debate and the rest (myself included) had only prepared jokes.

At the end there was a question and answer section. Some members of the audience asked jokey questions relating to our topic. The university bigwigs answered them. Everyone laughed.

Then my brother stood up and asked why there were no intellectually disabled people on the panel, or as students, or as lecturers. He asked why there were hardly any people with Down syndrome in books, or songs, or plays, or movies. All the art forms we taught and sought to understand at the university.

The auditorium fell silent. Maybe because of the question, but probably because my brother has Down syndrome.

One of the university bigwigs stood up, cleared his throat, and gave as sensitive a response as he could. “Integration and representation are important issues but this is a forum for levity,” he said, “and your question is not one to be laughed at.”

My brother sat down. His question went unanswered.

When the debate was over my brother and I had the first real fight we’d ever had. I said he was a grandstander and an attention hog and that these were the people who could give me a job (or not) when I finished my PhD. Why did he have to ask that question, I asked. Why couldn’t he just shut up. Why couldn’t he just fit in? I said all the stuff I had never said before and had never even allowed myself to think.
Afterwards, I felt terrible and apologised. My brother said it was okay and that he was sorry too. We got over it.

But his question remained unanswered.

If integration and representation were important issues, like the university bigwig had said, why had no one tried to answer my brother’s question?

Maybe because as Leonard Davis wrote in his 2002 book *Bending Over Backwards* there’s,

> a strange and really unaccountable silence when the issue of disability is raised (or, more to the point, never raised)… the concept of disability has been relegated to a sideshow, a freak show at that, far away from the academic midway of progressive ideas and concerns.

The thing is, I still can’t answer all the questions my brother asked that day.

I don’t know why there is such a culture of low expectation towards people with Down syndrome specifically. I don’t know why those expectations feed into our cultural understanding of what people with Down syndrome achieve, especially when so many of us have lived experience that says otherwise.

I don’t know why there were no students, or lecturers with Down syndrome at my university that day. But, after five years of research and study, I can answer why there are very few representations of Down syndrome in narrative fiction.

So, my brother Charlie, pretend I didn’t yell at you that day after the debate. Pretend I said this instead…

In 2012, the Global Down Syndrome Foundation stated that 38% of the population knew someone with Down syndrome.

In 2013, the National Dissemination Centre for Children with Disabilities said that:

> Nearly 5,000 babies are born with Down syndrome in the United States each year. This means that 1 in every 733 babies is born with this condition.

But, despite this lived experience, there is still a crisis of representation around Down syndrome, particularly in narrative fiction.

Characters with Down syndrome are extremely uncommon, narrators with diagnosed Down syndrome are few, and sole narrators with Down syndrome are basically non-existent.

Why? After all, readers don’t just respond to novels with characters who have Down syndrome, they devour them. Novels like *The Memory Keeper’s Daughter* (2005) by Kim Edwards and *Jewel* (1991) by Brett Lott have sold millions of copies. Having said that, only a certain type of adult novel about Down syndrome is popular.

**The Down ‘S’yndrome Novel.**

The Down Syndrome Novel refers to a novel that builds the scaffolding of plot and story around the inclusion of a character with Down syndrome, making this character necessary for the plot. If you remove the character with Down syndrome (or their disability) from the narrative, the plot caves in.

I coined the term Down Syndrome Novel in my PhD thesis in order to discuss the style of narrative where Down syndrome is included. I refer to these narratives as Down Syndrome Novels in order to reflect importance of the syndrome within the narrative structure.

Thus, I also chose to eschew the contemporary lower case ‘s’ for the more traditional (and now almost obsolete) upper case ‘S’ in order to immediately identify the otherness central to these novels. This is not to criticise the Down Syndrome Novel, but rather to present a line of difference between depictions of Down syndrome and those novels where Down syndrome is indispensable to the plot.

Building the syndrome into the plot is the most important element in the Down Syndrome Novel, and also the most limiting aspect for the character with Down syndrome.

Why? Because the Down Syndrome Novel is rarely (if ever) told through the perspective of a person with a disability: they are largely told by parents.

In telling the novel through the parent’s point of view the novel often presents the disabled character as an unexpected, and often unwanted, presence.

Whether this is as a child in the parental narrative, the forced friendship/sibling relationship, or a persistent (often sexual) threat, these narratives rely on archetypes of Down syndrome to form the spine of the narrative and these archetypes almost always exist somewhere on the polarised spectrum between monstrous and angelic.

The Down Syndrome Novel centres around disability and almost universally presents the character with Down syndrome as a problem within the narrative that the narrator must learn to overcome. This movement towards acceptance is the character arc, narrative problem and eventually, the plot. In creating, and thus remaining, within these character definitions the author builds clear and impenetrable boundaries around the disabled character, and the novel including a character with Down syndrome becomes a novel almost exclusively about Down syndrome.

Having said that, the Down Syndrome Novel tries. It tries really hard to create an environment of social diversity and change.

In fact, in seeking to become a dynamic force in social change, the Down Syndrome Novel often traps its hero beneath an avalanche of narrative expectation. Often the only way to remove this expectation is for the character to become incidental to the plot.
a character in a story, not necessarily about Down syndrome, disability or social stigma and inclusion.

However, being “incidental” to the plot carries its own difficulties and silences. The incidental character with Down syndrome may be freer within the narrative, but this character will never be free to tell their own story.

Mitchell and Snyder discuss this gap in their book *Narrative Prosthesis* (2000):

> The marginality of disabled people has occurred in the midst of the perpetual circulation of images of disability.

The marginalisation of the character with Down syndrome in narrative fiction is not about appearing in a novel, but having a voice and agency within the narrative. When writing about the intellectually disabled, few authors have situated themselves comfortably between the content of a character’s experience and the style necessary to accommodate difference.

**Angel or monster**

Representations of characters with Down syndrome have historically fallen into two polarised categories – angel and monster – with few transcending the boundaries to become fully realised characters with their own autonomous voice.

This lack of freedom in voice is generally connected to the fear of the character with Down syndrome and their inclusion into the world, even an imagined world.

Fear, of the body growing into adulthood while the mind stays behind in childhood [sic]. Fear, of how the first-person voice of a character with Down syndrome might change the landscape of the modern narrative, and perhaps even fear that the character with Down syndrome will transgress all normative boundaries.

These fears, felt and expressed by the writer, narrator and reader, are all ingrained in this lack of voice. These elements, when combined, create a culture of low expectation of the character with Down syndrome within the narrative.

The disabled character is often used to illustrate and embody a theme that exists outside their interior world. In her paper *Depictions of Intellectual Disability in Fiction* (2007) Anupama Iyer, consultant psychiatrist in adolescent developmental disabilities for St Andrew’s Healthcare, discussed this connection.

She wrote:

> “A character with an intellectual disability [is] a silent Rorschach ink blot onto which society projects its devices and desires.”

In an interview regarding his particular interest in intellectual disability author Mark Haddon supported this statement when he said:
“For me, disability is a way of getting some extremity, some kind of very difficult situation, that throws an interesting light on people.”

Here, Haddon identifies that disability is the key he uses to create conflict, and he isn’t the only one. In fact, most Down Syndrome novels use disability to create the central narrative conflict and, while these novels have clearly good intentions, this conflict only serves to distance the character even further from the reader. It makes Down syndrome “other”.

Most characters with Down syndrome, particularly within the Down Syndrome novel, are heterosexuals from white, middle-class (although often the families fall on hard times) multiple-children families. They are heavily normalised by the author and a narrative voice outside their intellectual disability but, as an intellectually disabled “Other”, characters with Down syndrome are sometimes capable of stretching their own limits using the vehicle of their disability.

In William Faulkner’s The Sound and the Fury (1929) Benjamin’s behaviour is heavily normalised by his family, particularly his sister Caddy. Benjamin - who has an unidentified severe intellectual disability - is admonished and condemned but any strangeness or disturbance in his behaviour is expected. He can use his disability for attention, and affection, and this is why, when he forces his hand through the fence, he unable to understand the terror and disgust he finds there.

While Benjamin is not capable of moving beyond the property borders unpunished, it is still possible for a character with Down syndrome to find freedom in traversing the boundaries of normative behaviour.

Dissolving boundaries

In my Gothic Tasmanian novel Sing Fox to Me (2016) I was extremely conscious of representing and dissolving boundaries around my protagonist with Down syndrome, Samson Fox, in order to create a narrative where Samson was free to move, evolve and change.

Because, just as a person with an intellectual disability has the right to be a “significant member of society”, so does a character with Down syndrome have a right to a belonging within the story that does not build them into the scaffolding of the narrative.

In her book Greater Expectations (2010) disability researcher Jan Gothard writes:

> Inclusion means more than simply having people with disabilities in mainstream classrooms and workplaces. It’s about the state of mind which sees people with disabilities accepted as valued, significant and worthwhile members of society: people who have every right to belong.

When I started writing Sing Fox to Me, I wanted to understand why characters with Down syndrome didn’t seem to match up with the lived experiences expressed in books like Jan...
What I discovered is that the world both within and outside the novel is still struggling to understand the limits and expectations of Down syndrome.

Down syndrome is still something of a mystery because it is largely represented through archetypes, and images folded down through literature. There is in fiction, as there is in life, a culture of low expectation.

Ultimately, I do not expect to fill the gap in representations of Down syndrome within narrative fiction – no single author could – and my novel was certainly never intended to be the final word on how characters with Down syndrome could function within the novel.

After all, the novel is forever changing, and my hope is that characters with Down syndrome will diversify and change with it. My character with DS, Samson Fox, can be part of this change but he can’t carry the full weight of his disability. Samson can only tell one fictional story. He is only one voice in a symphony of what could be thousands, maybe even 1 in every 733.

I started questioning depictions of Down syndrome in fiction and writing Sing Fox to Me with the express purpose of changing something.

I wanted to change the world inside my library. I wanted to open a book and see a character with Down syndrome. I wanted to hear his voice and see inside his head. I wanted to know what he thought.

However, once the novel was finished and printed, I realised that what I really wanted to change was me. I wanted to be able to write about something I had yet to see in fiction, but I also wanted to show other authors that they could have higher expectations of characters with Down syndrome.

I wanted, as Foucault once said, to write a “book so that other books are possible, not necessarily written by me”.

My brother, Charlie, what do you think? Does this answer (at least part of) the question you asked that day at my university debate?