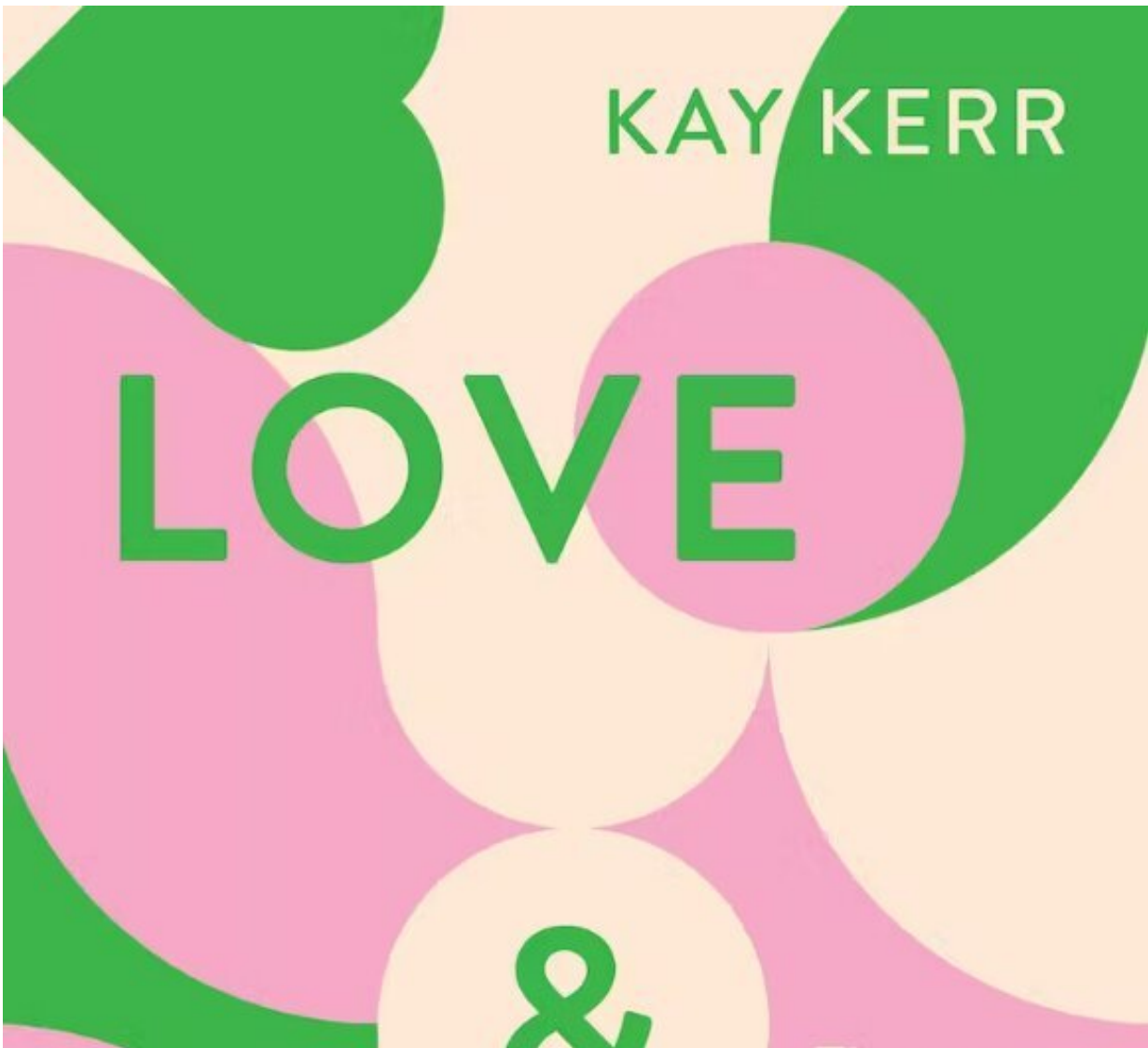


Autistic people often feel they're 'doing love wrong,' but there's another side of the story

April 24 2023, by Amanda Tink



Credit: Macmillan Australia

"Love has always intrigued me," writes autistic author Kay Kerr, "in part because I have carried for a long time a feeling that I am doing love wrong."

Kerr is the author of two young adult novels with autistic protagonists. In her third book, "[Love and Autism](#)," she returns to her journalist foundations to explore how love and autism shape each other.

The book is supported by a significant amount of research, but its heft is in the life stories of five autistic Australians: Jess, Chloe, Noor, Tim and Michael. While the book shows they all have experiences in common, each has a cultural point of difference from the others: Jess is a lesbian, Noor is from Malaysia, Chloe has an autistic partner, Tim is nonspeaking, and Michael is from a regional area.

Three of the five might already be known to readers. Noor [writes](#) about being autistic and Muslim. Tim has given [a TED Talk](#) and published a book, [Back from the Brink](#). And Michael appeared in the first series of [Love on the Spectrum](#). Through interviews with Kerr, each narrates their experience of the many types of love that have inflected their daily lives, from childhood through to adulthood.

Exploding myths

For me, as an autistic reader, a whole book of [autistic people's](#) experiences of love is both thrilling and saddening. It is thrilling because it is even more thoughtful, practical and delightful than I imagined it could be. It is saddening because, as far as I'm aware, such a book has not been written before. This shows how deeply the myth that autistic people are incapable of love is ingrained.

So many autistic people feel, like Kerr, they're "doing love wrong." We are the children who don't hug their parents, the friends who don't attend

the milestone birthday party, and the partners who don't offer comfort when their partner is upset.

There is another side to these situations: Mum just put her strong-scented perfume on; going to the shopping center to buy the perfect birthday gift was exhaustingly overwhelming; and we thought our partner meant it when they said they wanted to be alone.

But this side often remains unacknowledged, and autistic people continually receive the message that, in every situation involving any type of love, our communication is flawed—and, by extension, so are we.

As Kerr writes: "The feedback I received on a loop from childhood through to becoming a young adult was that, nope, that is not how it is done. You are doing it wrong."

'Refrigerator mothers' and other misinterpretations

Since the 1940s when autism was first designated as a diagnosis, the causes of our communication differences compared with non-autistic people have been continually debated.

Leo Kanner changed his mind a few times before concluding ["refrigerator" parents were to blame](#); especially women who attended university, or who worked after they married. (He finally retracted his theory in 1969, but by then Bruno Bettelheim's redeveloped version of it was already more popular.)

By the 1980s, as parents strengthened their advocacy against these untrue portrayals of their parenting skills, researchers shifted their attention from them to their autistic children. If autism wasn't a "normal" mind destroyed by outside influences, perhaps there was no mind, or

awareness of mind, to destroy, they speculated.

David Premack and Guy Woodruff had recently coined the phrase "[theory of mind](#)" to describe the ability to attribute [mental states](#)—emotions, beliefs, intent—to ourselves and others. Simon Baron-Cohen, Alan Leslie and Uta Frith believed [a lack of theory of mind](#) would explain autistic children's "failure to develop normal social relationships" and their "poverty of pretend play."

To [test this hypothesis](#), they asked preschool-aged children to answer a question about a doll's understanding of a particular situation, using "normal children and those with Down's syndrome" as control groups.

They stated that the results proved: "Even though the mental age of the autistic children was higher than that of the controls, they alone failed to impute beliefs to others." But four of the [autistic children](#) gave the correct answer, while four of the "normal" children gave the incorrect answer (in groups of only 20 and 27, respectively).

Research groups have since been unable to replicate the [1985 study](#) (or other theory of mind studies) on humans. Also, many other groups of children give the incorrect answer in this type of task. These groups include children who are blind, or deaf, or epileptic, as well as children who have fewer siblings, or fewer adult relatives living close by, or whose family has a lower socio-economic status.

In fact, as Morton Gernsbacher and Remi Yergeau [point out](#), and as anyone familiar with the many problems with IQ testing might have guessed, a significant predictor of theory of mind test results is language skills. Yet the myth that autistic people lack theory of mind remains unjustifiably popular.

The parents of both Tim and Michael, the only two subjects of "Love

and Autism" who were diagnosed autistic as infants, were told their children would never show love and empathy for anyone. It's lucky these parents knew better than to believe this, but when Kerr's daughter was diagnosed autistic 20 years later, little had changed.

She writes: "No doctor ever told me: 'Sometimes your child will be so happy her squeals will pour out of her like golden light. Her body will not be able to contain the energy and will move in motions of the purest freedom you have ever witnessed. She will draw more happiness from feathers than you would have thought was possible from anything. She will learn more about what she likes than you could ever dream of knowing, and you will find yourself loving those things, be they dragons or fairies or Pokemon or crystals, with more enthusiasm than you thought your mind contained.' No doctor ever told me this, but I wish they had."

The double empathy problem

It's true that autistic people sometimes struggle to understand non-autistic communication. Yet it's equally true that non-autistic people sometimes struggle to understand autistic communication. In 2012, autistic researcher Damien Milton published [his own theory](#) of autistic and non-autistic communication differences (one that has been replicated): the "[double empathy problem](#)," which explains these differences as cultural.

Milton's model emphasizes that neither group—autistic or non-autistic—lacks the ability to communicate. They simply communicate better within their own group. As Jess explains:

"With someone [neurotypical](#), I'll have to explain how I got from point A to point B, because they don't understand the connections. And then I have to backtrack and think, 'How did I connect those two thoughts?'"

Because I won't know. "

When autistic people are labeled as lacking theory of mind, they are made entirely responsible for the success of something that is supposed to be reciprocal.

The solution to the double empathy problem is for both cultures to be accommodated, rather than autistic people being expected to conform to non-autistic culture. This is also Kerr's conclusion about herself:

"I was doing love wrong [...] because I was intent on acting like a neurotypical person, and in order to do that I needed to smother, bury, deny and hide my autistic tendencies and needs."

Rediscovering and affirming one's autistic needs is a long process. For Kerr, writing "Love and Autism" helped.

A 'proudly autistic' book

Structurally, too, this book is proudly autistic. Nobody's story dominates. It is divided into five sections, which feature experiences from the same period of life of all five subjects. Yet although the sections are in chronological order, the order of the subjects within each section is different each time. In this way, the book as a whole charts a leisurely, meandering path, with additional digressions into research—and stories from Kerr and others—as it goes.

Nevertheless, as you read, you'll find many connections between all five stories. Kerr says,

"My brain adores patterns, finding them in the way I imagine neurotypical people might find something inconsequential to add to a light conversation: with ease. As I pored over the notes from my

interviews, the patterns started to emerge. The stories are all so different, but familiar too."

The five subjects of the book each describe their own versions of discovering and affirming their autistic needs. All were stifled by the expectation to perform non-autistically, and they share the tremendous effort masking (or acting non-autistically) entailed. When they learned to understand autism as a characteristic rather than a deficit, they began to thrive.

At school, Chloe was both bullied and ostracized due to her talent for math and her direct communication style. As a result she spent most of her schooling alone, and did not skip a grade as her teachers suggested, because she thought the bullying would then increase. As a university student, however, math led her to engineering, and her direct communication led her to becoming an advocate for disabled students.

Now, she is determined to find a workplace that values her autistic characteristics:

Authentically loving ourselves and others

The five autistic people profiled share a range of ideas for how to authentically—which for them, means autistically—love themselves and others.

Chloe explains about her relationship with her partner Jacob, who is also autistic:

"We have a lot of fun that maybe neurotypical couples don't, really. You know, there's this stereotype of the childish joy autistic people can still hold on to, and I think we can find that. Like for Easter I will still do an Easter Egg hunt for Jacob, and make a big thing of wrapping presents to

put under the tree at Christmas, because I really enjoy doing that, and Jacob gives me incredible reactions when I do. Just little joyous moments like that. We also echo each other, like whatever echolalia we have picked up for the day we will bounce back and forth."

There are also examples of how autistics and non-autistics can complement each other in relationships. Michael, who was ignored for most of school, reflects on the friendship he developed with schoolmate Briana, which continued after they graduated:

"She is like a grasshopper; she bounces around from one place to another. I think, if she didn't have me in her life there would be more chaos, and if I didn't have her, my horizons would not have been expanded."

The creativity and vibrancy of the autistic community features in each person's story. Tim experienced a lot of discrimination throughout his schooling. He says,

"There are so many challenges in a world that doesn't understand, acknowledge or accept diversity I won't be able to list them all. Because of these challenges, I find autistic people learn to be resilient and to navigate the world with our strengths of mind, heart and purpose."

For Jess, connecting with the autistic community made it possible for her to relate to her diagnosis and understand its complexity:

"When it's somebody talking about it from the inside, instead of cold, clinical, diagnostic language ... it's no wonder I looked at my initial diagnosis and thought that can't be me, because it was all looking from the outside, not exploring how when X happens you react like Y because of Z [...] So yeah, sharing and connecting with community has been really good."

Navigating discrimination

Noor wants to teach her autistic daughter to value the strength of her autistic brain:

"I will definitely say to her that it's the way Allah created you and me. And there's nothing ever wrong in that. Even if the wider world or people who are not very kind say that [it is], don't ever believe it. I will tell her: I'm your biggest ally, and you're perfect as you are. Basically, all the things I wish I had heard from my parents when I was growing up."

As an autistic woman who navigates being both Muslim and Australian, she explains:

"It's really complicated as well. I'm not an out-and-proud autistic Muslim woman of color. I'd like to be at some stage, when it's safer, because I don't ever want my daughter to feel ashamed of who she is, or who I am."

Her observation highlights the reality that disclosing an autism diagnosis carries real risks of discrimination, particularly when you belong to other minority groups.

And perhaps this is part of the reason for the absence of one element that I had hoped to find in a book featuring autistic Australians: Aboriginal and Torres Strait Islander people. However, I don't believe Kerr herself is responsible for this omission. Part of that responsibility belongs to the research community.

The [first research](#) specifically focusing on First Nations autistic people was only published in 2020. And I have not been able to find Australian research on autism that ensures First Nations people are among those surveyed.

Equally importantly, the entire Australian community is responsible for creating a society where it is safe for any Australian to identify as autistic. "Love and Autism" works towards this society by presenting autism as a human condition to be understood, rather than a medical condition to be pathologised.

It also reminds autistic people—especially those who cannot safely identify as autistic to the people around them—that understanding and acceptance is available within the autistic community.

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