Journal of Popular Romance Studies
published in partnership with the International Association for the Study of Popular Romance

Mattlin, Ben. *In Sickness and in Health. Love, Disability, and a Quest to Understand the Perils and Pleasures of Interabled Romance*. Boston: Beacon Press, 2018. 258 pp. US $27.95 (softcover). ISBN: 9780807058541.

Review by Martina Vitackova

"When it comes to sexuality in the disabled, dismissal is apt to turn into outright repression" states Nancy Mairs in her essay *Sex and the Gimpy Girl* (Mairs 2009: 8-9). Indeed, western society generally prefers to infantilize disabled people and think of them as asexual beings. Nothing is farther from the truth, shows the disability activist Ben Mattlin in his new book. The author, known for his biography *Miracle Boy Grows Up* (2012), addresses interabled relationships in all their complexity and normalcy, fighting the idea that interabled couples are either tragic or noble. Mattlin interviewed fourteen interabled couples, including himself and his wife Mary Lois, about the "perils and pleasures" of their relationships.

In his interviews Mattlin included a range of couples, varying in disability, race, age, gender and sexual orientation, striving for what he calls "gender fairness" (46). The diversity scale of the book includes, for example, the Asian – African American couple Wanda and Kevin (33), Alisha and Jared, facing Jared's PTSD after his deployment during the Iraq War (63), and the aging lesbian couple Christina and Janet (186). However, Alisha and Jared are the only couple facing a non-physical disability and there is quite a limited scale of physical disabilities represented, with most participants being para- or quadriplegic due to disease or accident. With the exception of one Canadian couple, all the interviewed couples are from the United States. Some of the couples started off as interabled, while some faced together the shift to disability for one of the partners. The most harrowing example in the book are probably Rachelle and Chris, who received a lot of media attention after Rachelle became paralyzed due to an accident during her bachelorette party, just days before their planned wedding. That postponed their wedding for two years but did not break them up: their relationship "proved to be strong" (54). The last interview includes recently widowed Colleen who reflects upon her thirty-five years of marriage to the disability rights advocate and quadriplegic Max (214).

While Mattlin might have striven for an intersectional approach, the lower class is strikingly missing. He does, however, address the insufficiency of state and federal aid for the disabled in the US on multiple occasions (e.g. 40, 67, 118). On the other hand, a lot of attention is paid to university education—when present. Having a "Harvard pedigree", as he describes it (151), makes Mattlin very receptive to the received education and family background of particular interviewees, which does betray a certain elitist approach. "Dorene and I were at Harvard together," he would mention (140) discussing her relationship with the "mild-mannered Yallie" Steve (141) who after Yale "earned a PhD in linguistics at UC Berkeley" (142). Another aspect worth mentioning is that many of the disabled interviewees are disability activists, book authors, journalists, bloggers or YouTubers—like Simi Linton, the author of *My Body Politic: A Memoir* (2007) or Shane Burcaw who has published three books so far and has, together with his girlfriend Hannah, a blog and a YouTube channel dedicated to his life coping with SMA. These are undoubtedly people who already have media visibility and therefore an opportunity to have their voices heard. Conversely, several couples opted to use fake names in order to protect their identity. This proposes quite an interesting question about the position of disabled people in contemporary society that, unfortunately, remains unaddressed.

The book is divided into four parts, tracking interabled couples in different stages of their relationships—*First comes love (and sex)*; *The long and winding road*; *Aging with disability, or with a disabled partner, and other joys*; and *Twenty/Twenty hindsight (the long view)*. The central question of the book is whether disability draws a couple together or pushes the partners apart: is it a bridge or a wedge? (85). The answer is, as you might guess, somewhere in the middle. For all interviewed couples the situation constantly oscillates between the two. An important aspect of the everyday lives of interabled couples is the "constant balancing act" (42) between the privacy/bodily autonomy of the disabled partner and the care they require from their partner or other helpers (if available). Considering this matter, the author himself describes his feelings towards his wife as "a warm, oozy mixture of gratitude and insecurity" (83). At the end of the book, Mattlin concludes that "the way couples negotiate their differences and shared responsibilities has more to do with their personalities and individual strengths and weaknesses than any disability either one might have" (153). He realizes that "the credit is also due to stubbornness, open-mindedness, creative problem-solving, conscientious communication, ingenuity, luck, financial support, patience, and a monumental revolution in legal and cultural attitudes toward people who are marginalized, who are deemed different" (229).

"'How do you help her when you're angry, and by the same token how does she ask you for help when what she really wants is to run over your toes?' (Believe me, I know whereof I ask)," Mattlin challenges the able-bodied partner Tim (116). The heavily tattooed Laurie who was born with SMA (just like Mattlin, Shane and Kevin) and her muscular husband Tim, eight years her senior, are living in Canada and therefore can make use of the social and health care system that makes their lives much easier than the other interviewed couples—who are all American. "I'm left with the feeling that this is the couple with whom I have everything and nothing in common," Mattlin concludes (120). This "knee-jerk cynicism" (102) about himself and others sometimes supports, but more often comes in the way of someone else's narrative. The voice of the other interviewees are frequently muffled by the ongoing commentary of Mattlin who, instead of letting his participants speak for themselves, narrates and comments on their experiences and opinions, and relates these to his (and his wife's) own. He interrupts, for example, the narrative of Alice and Bill to share a story of him and his wife fighting the phlegm that has obstructed his airways (89-90). This episode does, indeed, illustrate the complexity of an interabled relationship and the constant juggling between love and care, but also inevitably steals the spotlight from the interviewed couple. “For me, it’s interesting to contemplate this particular disability perspective.” On another occasion, Mattlin feels the need to interject (24) when another interviewee tells him that on a date he would assess whether his partner would be physically able to lift him up. At times, this self-reflective commentary works and presents the reader with a sort of situated knowledge: “‘Of course,’ I say, to sound sympathetic (but I fear it comes off as avuncular or even condescending).” (58). But in general, the text is crowded with Mattlin’s presence; him thinking, realizing, mentioning, pointing out, suggesting, to such a scale that you could hardly call the discussed cases interviews. There is also very little space left for the reader to form their own opinion. Regrettably, the author’s strong presence is sustained in the conclusion (229-38). While one of the interviewees says that she hopes this book “helps other families” (80), Mattlin again turns in the conclusion to himself and his relationship and wonders what the writing process did to him and his thinking about his own marriage.

Disregarding the strong authorial presence, Mattlin’s book is an important addition to the work of Nancy Mairs or Mark O’Brien, who have both used their own personal experience to address the issues of love and sexuality for disabled people, and to autobiographical writing about the disabled bodily experience concerning love, romance and relationships. While Mattlin also clearly draws from his own personal experience and the lived reality of his marriage, there is an attempt to present a multiplicity and diversity of voices, which surely should be complimented.

References

Mairs, Nancy. "Sex and the Gimpy Girl." *River Teeth: A Journal of Nonfiction Narrative* 10.1-2 (2008): 3-10.

O'Brien, Mark. "On Seeing a Sex Surrogate." *The Sun* 174 (1990).