

BOOK REVIEW

Living and narrating disabilities

GAYATHRI PRABHU

K Srilatha, *This Kind of Child: The 'Disability' Story*, Westland, 2022, 336 pgs, INR 409 (paperback), INR 388.55 (Kindle). ISBN-13: 978-9395767521.

The reader lingers, broods over the sea-green cover of K Srilatha's *This Kind of Child: The 'Disability' Story*. Against a faint grid of squares, the title's typography that evokes handwritten text doubles up as a striking cover image: two alphabets ('h' and 'c') are flipped in the opposite direction. Even as the reader takes in that moment of alphabet-rebellion, the quotation marks around "disability" start to niggle. What is it evoking? As with any movement, the wholehearted embracing of shared terminology becomes a crucial starting point for advocacy, and disability rights has done so for decades. Nonetheless, having decided to accept the tentative, discursive connotations of punctuation, the reader now has to contend with the question of authorship. Although featuring the name of a single author on the cover, the work shows all the qualities of an edited volume — apart from select fragments by the author, the bulk of the book comprises of contributions from other writers or verbatim interviews. How do we make sense of multiple stories and multiple authors ("the stories of an entire universe of human hidden in plain sight" as claims the Preface) merging into one story (with quotation marks) by one author? What might this tell us about ethical considerations around disability narratives, especially if reaching out to a larger readership?

It took this reader several sessions of dipping in and out of the text, several days of mulling over it, to finally see the whole situation from a more comfortable perspective. The explanation may be located in the position that K Srilatha takes in her exploration of the experience and discourse of disability. This experience as "the mother of a child who did not fit in the school system, a child who was disabled by it" (p xi) becomes the opening and closing frame for the

book. The participatory approach is adeptly pitched to counter "the systemic violence of institutions which fail human beings and punish them for inhabiting certain bodies, certain minds" (p xi). It facilitates for the author an embodied and empathetic position of being interrogator/listener as well as a curator/advocate of a wide range of experiences and insights into the inhabitation of distinct bodies and minds.

The reader is thus privy to the author's highly attuned awareness of differences and participatory boundaries. We sense this in the precision of the questions being asked, in the determined avoidance of any "tidying" of experiences, and a conscious choice to accommodate all manner of genres, voices and expressions. The descriptions and accompanying terminologies around abilities and disabilities are left to the discretion of all the speakers. In fact, the readers are often likely to be guessing what condition or impairment is being talked about. This indeed reflects the emphasis that Disability Studies places on the shift from a medical model (more diagnostic, or attributed to individual bodies) to a social model (more cognizant of environments and contexts). Towards such complex navigations, the author astutely turns into an attentive, unobtrusive chronicler, while the strategic tentativeness of both terminology and authorship thus turn into the book's strength.

Having traced the deliberate heterogeneity in the design and treatment of the book, the reader must also factor in the possibilities offered by the structure of the book. A note by the author explains that notwithstanding the diversity of genre — personal essays, interviews, conversations, and short fiction — the organising logic is thematic. These comprise of the perspectives of i) young people whose learning styles may be at odds with conventional schooling (the memoir frame to the whole project), ii) persons who identify as disabled, iii) narratives of seeing and sight, iv) parents of children with disabilities, v) siblings and children of persons with disabilities, vi) teachers and others who support persons with disabilities, vii) K Srilatha's "inter-leaved" prose fragments that can be read as autobiographical fiction or autofiction.

The author is understandably wary of linking the community of persons with disabilities too quickly with advocacy or activism. "Like everyone else, persons with disabilities vary in their ability to articulate experience, to advocate for themselves and for others. [...] For isn't this all equally about inter-being?" (pp 18-19). To comprehend the author's

Author: **Gayathri Prabhu** (gayathri.prabhu@manipal.edu), Associate Professor, Manipal Centre for Humanities, Manipal Academy of Higher Education (MAHE), Manipal, Karnataka, INDIA.

To cite: Prabhu G. Living and narrating disabilities. *Indian J Med Ethics*. Published online first on May 24, 2023. DOI: 10.20529/IJME.2023.034

Manuscript Editor: Sanjay A Pai

Copyright and license

© *Indian Journal of Medical Ethics* 2023: Open Access and Distributed under the Creative Commons license (CC BY-NC-ND 4.0), which permits only non-commercial and non-modified sharing in any medium, provided the original author(s) and source are credited.

integrity to this stance, one might recommend a sparse but moving section called “I Should Not Ask Random Questions: A Conversation with Gayathri” which is presented in an interview (Q&A) format. The respondent (Gayathri) is twenty-six-years of age and on the autism spectrum. Between the respondent’s voice (pithy, factual) and the author’s questions is the added interjection of the founder-director of the foundation where the respondent works. What starts off as an exchange of data collection (of Gayathri’s life and routine) takes a fascinating turn when the respondent is encouraged to ask questions of the interviewer. Gayathri worries aloud about asking random questions (“Are you married?” she asks Srilata) and yet we know that her question is no more random than what Srilata has been asking her for the preceding four pages (p 61). It is the recurrence of such randomness of human entanglements that become the purposive spine of K Srilata’s project.

The missed opportunity of the project, however, is that it could have extended to collate an appendix of resources for support with disabilities; contact details of organisations, information about medical and legal rights, and so on. Considering that there are so few books on the subject in India and equally patchy efforts towards institutional disability support, this was probably one ethical imperative that needed addressing. It is also fair to expect more diversity in sources rather than the likelihood of most narratives coming from the same social/professional circles. The resultant strengths or limitations of geography and demography (as with any edited volume) could have been explicitly addressed or reflected on by the author.

Inevitably, the book has to contend with the borderlines that emerge when capturing close interactions between people with disabilities and people who likely identify as able-bodied (at times designated as caregivers). K Srilata’s efforts to articulate and present the mutual enrichments of such interactions thus become especially poignant. For instance, the interview with VR Krishnan titled “He Was Mine to Look After” about an older person (in their seventies) caring for a younger sibling (in their sixties) with Down Syndrome. While the respondent is frank about the challenges and responsibilities of being a primary caregiver, the accent of the questions/conversations falls firmly on *care* and its multi-directionality. A memory of his brother surfaces for Krishnan, “When my daughter and son were born, he used to take care of them, keep the feeding bottle to their mouths and untiringly swing the *thuli* (cradle-cloth) till they fell asleep” (p 182). The cradle-rocking image stays with the reader, and this vivid immediacy is a constant feature across the varied components of the book. It may have something to do with K Srilata’s superlative instincts and skills as a poet. She develops the book from details, large and small, quilting together of narratives even while resisting a perfunctory resolution.

This Kind of Child mirrors the author’s own experience of the project which she describes “as though many doors have been thrown open and all at the same time” (p 313). The book is thus a vital addition to the ongoing discussions on the ethics of care in India.