



**Gail H. Landsman.** *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies.* New York: Routledge, 2009. xii + 276 pp. \$130.00 (cloth), ISBN 978-0-415-91788-9; \$36.95 (paper), ISBN 978-0-415-91789-6; ISBN 978-0-203-89190-2.



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## A More Nuanced View: Mothers' Perspectives and Disability Theory

The knowledge particular to mothers who parent children with disabilities has frequently been dually disregarded: first, by the medical establishment as too mundane and specific to have scientific relevance; and second, by disability activists, many of whom view mothers's perspectives as too frequently aligning with medical and rehabilitative models of difference that perpetuate ableism. Gail Heidi Landsman (herself the mother of a daughter with cerebral palsy) argues for a re-interrogation and re-integration of mothers's perspectives. Writing from a vantage point that combines the insights of feminist theory, disability theory, and feminist medical anthropology of reproduction, Landsman asks what attention the insights of mothers might add to both medical discourse and to disability theory. Presenting extensive ethnographic evidence based on years of fieldwork with American mothers encountering children's disability diagnoses in upstate New York, Landsman argues that a scholarly practice that attends to the narratives of mothers holds critical potential for our understanding of applications of medical diagnosis, and for ongoing debates

about the limits of the medical model of disability and the impairment-disability dichotomy.

Landsman sets out to do several things in the course of this book. First, she seeks to contribute to the ethnographic record an elaboration of the moment of diagnosis in the contemporary American clinic. Drawing on participant observation during these clinical encounters and follow-up interviews with mothers recruited to participate in the project, Landsman documents the kinds of interactions, conflicts, misunderstandings, and shared hopes that pass between healthcare providers and mothers. On this front she finds that while both clinicians and mothers have the best interest of the child in mind, misunderstandings arise when clinicians push for a pragmatic leveling with worst-case-scenarios, while mothers prefer to maintain a hope for a child's ability to overcome initial diagnostic indications. This tendency of mothers raising children with disabling conditions to align themselves with an "overcoming" discourse of rehabilitation, has been maligned by disability scholars for the ways in which hoping for "rehabilitation" further in-

scribes the dehumanizing gaze of ableism, which denies the ability of people with disabilities to live rich, full lives.

Second, Landsman sets out to think through the subsequent manner in which mothers come to view and talk about their disabled child, and about themselves as mothers of a disabled child in, as she aptly puts it, "the age of 'perfect' babies." Landsman argues that while mothers do in fact at first seem to align themselves with the rehabilitation narrative, they subsequently come to articulate in their own terms the ways in which disability is systematically otherized in U.S. society, and therefore shares characteristics with other systemic forms of oppression like racism and sexism. Therefore, the same mothers who at first hope for and speak about a "cure," often subsequently become advocates for disability justice in their own time. In order to explain how this "change" in fact makes sense as part of the continuous subjective experience of mothers coming to terms with parenting disabled children, Landsman argues that throughout these trajectories of "hope" followed by a new political consciousness that recognizes disability oppression, mothers are at all points arguing and rooting for the personhood of their child in the best and most compelling language available to them. Landsman is particularly effective in demonstrating the ways in which the narratives of perfection that circulate around reproduction, birth, children, and parenting in contemporary North America serve to undermine, not only the personhood of infants pathologized by disability diagnosis, but also the symbolic personhood and motherhood of the mothers themselves.

Ultimately, Landsman argues in her final chapter that attending to the experience of mothers helps us to trouble the disability/impairment divide, a scholarly project that Tom Shakespeare began, and Devva Kasnitz has called to be the "cutting edge of disability studies." [1] Drawing on Kevin Paterson and Bill Hughes's notion of "dys-appearance"—wherein the impaired body appears as "other," and is brought to consciousness at moments when it fails to transverse a socially expected trajectory, but otherwise remains neutral and unremarkable to the subject-bearer (and, she argues, the day-to-day caretaker)—Landsman unpacks the conflicting and changing ways that mothers experience the dys-appearance of their own children's bodies. [2] While the reality of an impairment becomes normalized in the day-to-day lives of mothers and their children, the same body "dys-appears" or becomes manifest in social and developmental comparisons. The mothers in the study first resist the medical model because they fear being high-

lighted as abnormal, but subsequently come to see impairment as nuanced and variable, ultimately rejecting the medical model due to its moralizing weight that dys-appears impairments that otherwise fade into the background of daily life. Thus, Landsman carefully sketches the complex and nuanced ways that impairment "is produced as experience, albeit differently, for both disabled child and mother" (p. 203).

Beginning in 1995, Landsman's clinical research reflects a recent historical moment, "a time in mainstream North American culture when it was neither 'normal' to have a disabled child nor any longer socially appropriate to send such a child to an institution" (p. 4). Her research participants were contacted through their participation in the cultural scene at the Newborn Follow-up Program of the Children's Hospital of Albany Medical Center. She conducted participant observation during clinical encounters with doctors, nurses, counselors, and parents treating recently diagnosed or soon-to-be diagnosed infants and toddlers referred from neonatal care or pediatric practitioners. Landsman conducted in-depth interviews with sixty women whose children were determined to have a significant diagnosis as a result of their clinical encounter. The first in-depth interview occurred within a month of the diagnostic clinical visit, and a second interview was conducted with twenty-two of the original sixty participants roughly one year following the first interview. Landsman offers careful data regarding the socioeconomic, religious, ethnic, and educational backgrounds of the women she interviews, as well as detailing the range of diagnoses (from mental retardation to genetic disorders to missing limbs) conferred on their children. True to the ethnographic form, Landsman allows the mothers to speak for themselves and their voices to permeate her text, which is rich with paragraph-long examples drawn from interview transcripts.

In conversation with a body of work that examines how clinicians and patients use narrative to make sense of clinical encounters, Landsman argues that the same points of evidence may be employed, or read into narratives, differently by physicians and mothers. Especially, Landsman suggests that the same prognosis may be interpreted in terms of either hope (in the case of mothers) or denial (in the case of physicians's experiences of a mother's resistance to a negative prognosis). However, both parties maintain that they have the child's best interest in mind. Mothers think that they need hope in order to care for their child as best as possible, even if they on some level realize that this hope may ultimately be futile; doctors think that mothers need to accept a prog-

nosis in order to be pragmatically prepared for a difficult path ahead caring for a child who may never walk, talk, etc. Both have an eye toward the best possible outcomes for the child's future; however, their rubrics of analysis fail to match up.

For historians interested in disability theory, this book provides a look at the particular cultural context of late modernity in the United States, offering important examples of how theoretical concepts like medicalization, the medical model, and the impairment/disability dyad are articulated and relevant in the vernacular narratives of contemporary Americans. Those interested in childhood and family studies, moreover, will be interested to explore the ways that disability diagnoses influence not only the diagnosed, but also his or her kin. To the medical anthropology discourse, Landsman's book suggests points of divergence between healthcare professionals and mothers in their perception of interactions around disability diagnosis for infants and young children. And anyone interested in examining the lived experience of parents of children with disabilities across a myriad of temporal and cultural contexts will find Landsman's intricately thought-out and carefully plotted description of the motherhood role in the case of a child's disability irreplaceable. Future cross-cultural and historical investigations of similar subject matter deploying Landsman's well-developed framework will be of great interest to disability scholarship as a whole.

Some members of the disability community may be frustrated by Landsman's explanation of why some mothers continue to cling to hopes of normalization for their children (for instance, one mother whom she interviews talks about hoping that her daughter won't develop facial features that look too disabled); Landsman's observation that these comments and hopes represent an honest sentiment directed at protecting a child from discrimination may appear to some as a rationalization of ableist attitudes that leaves both the mothers and Landsman complicit in reinforcing normative standards of beauty. However, in my reading, Landsman is obligated to include an ethnographic account of this real position taken by some of her interlocutors. Moreover, her work presents a careful documentation of the ways in which these mothers are reacting to pervasive cultural narratives that threaten their own social value, thus providing important empirical documentation of ways that disability activists may intervene to mobilize parental sentiment to combat ableism.

While Landsman's research is rooted in her ethno-

graphic account of U.S. experiences of mothers who have newly received diagnoses and prognoses for young children, her ethnographic orientation opens possibilities for cross-cultural comparison. However, to this end Landsman herself only explicitly makes use of a few scattered international examples.[3] Moreover, while Landsman attends to the ethnic, class, and educational backgrounds of the mothers who participated in her study, the population that her study analyzed cannot be said to be representative of all parents in North America (nor does she claim that it is); for instance, her narrative offers a different parent trajectory than that of low-income urban black families documented by Carolyn Rouse in a contemporaneous study in California.[4] Additionally, some feminist anthropologists may observe that Landsman may have passed up an important opportunity for an investigation of the theory of motherhood, of the family as a sociological category, of kinship and subjectivity; although she engages feminist medical anthropology, she brings her observations around to bear on disability studies, but not on questions of relationality or interdependency and care.

Above all, Landsman's work constitutes an important, sensitively composed, and empirically impressive exploration of a subject that has enormous importance on the lives of people with disabilities (for who among us comes into the world without being mothered, or craving mothering, in some way?), and the future of disability theory.

#### Notes

[1]. Tom Shakespeare, *Disability Rights and Wrongs* (London: Routledge, 2006); and Devva Kasnitz, "Commentary: Collaborations from Anthropology, Occupational Therapy and Disability Studies," *Practicing Anthropology* 30, no. 3 (2008): 28-31.

[2]. Kevin Paterson and Bill Hughes, "Disability Studies and Phenomenology: The Carnal Politics of Everyday Life," *Disability & Society*, 14, no. 5 (1999): 597-610.

[3]. T. Ivry, "The Ultrasonic Horror Picture Show: Obstetrical Ultrasound in Israeli Public Spheres," paper presented at the Annual Meeting of the American Anthropological Association, Chicago, IL, 2003; T. Ivry, "At the Back Stage of Prenatal Care: Japanese Ob-Gyns Negotiating Prenatal Diagnosis," *Medical Anthropology Quarterly* 20, no. 4 (2006): 441-68; and M. Weiss, "Territorial Isolation and Physical Deformity: Israeli Parents' Reaction to Disabled Children," *Disability and Society* 12, no. 2 (1997): 259-272.

[4]. Carolyn Rouse, "If She's a Vegetable, We'll Be of Competing Metaphors in the Case of a Dying Child," Her Garden: Embodiment, Transcendence, and Citations *American Ethnologist* 31, no. 4 (2004).

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