DISABILITY AND MOTHERING: LIMINAL SPACES OF EMBODIED KNOWLEDGE

CYNTHIA LEWIECKI-WILSON AND JEN CELLIO, EDS.


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Reviewer Profile

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This book defies the adage “Don’t judge a book by its cover”. In fact, the cover of the book depicts liminal space between dense and leafless trees. The book explores the similarities between disability and motherhood. Disability is an embodied, situated, and social experience in culture that is constituted out of an ever-changing flow of relations among bodies, practices, institutions, personally experienced and socially constructed (Lewiecki-Wilson & Cellio, 2011, p. 3). Likewise, mothering is a relation to another and an experience in flux, an experience that is both personal and social, bodily and socially shaped by local as well as broader cultures.

The papers in the book raise questions about the figure of the mother as seen by feminist and disability studies. They also critique the notion of dependency and care in the philosophy of rationality and propose new models of interdependency. In the model of interdependency, the role of the mother is metaphorically constructed which is neither ideal nor whole but a divided and multiple subject, conveying the liminal state of betweenness, of one becoming two, or two conjoined but also separating to oneness (2011, p. 7). The papers address the covert eugenic practices carried out through reproductive technologies, in the political rhetoric of reproduction and in welfare policies of the current century.

The book is organised into five parts covering the multiple cultural forces flowing into bodies and shaping personal experience and flowing from personal engagement and resistance to reshape culture. The unconventional organisation of the book hints at the need to go beyond the boundaries of particular disabilities in terms of objects and methods. This review is more an annotation of the chapters of a book that is exceedingly rich in both content and context.

Part 1 Reproductive Technologies in the Disciplining of Bodies consists of four contributions which examine the various ways that technologies and discourses penetrate and reshape practices and expectations related to body.

Jen Cellio in her essay ‘Healthy, Accomplished, and Attractive: Visual Representation of “Fitness” in Egg Donors’ draws our attention to the neo-eugenic discourses of “improvement” through the “technologies of optimization” (Rose, 2007, p.16). The objects of her analysis are the photographs, various specifications, and detailed features of the egg donors and the location of advertisements: magazines catering to women’s health, fashion, parenting and professionalism, websites, and weblogs. These texts generate the illusion of an “ideal” donor, which in turn deems women seeking donor eggs as “unfit”. The author problematizes the role of analogy and metaphors in knowledge creation as “a task beginning with self-persuasion and ending with the persuasion of others” (Gross, 1990, p. 4). She meticulously dissects the role of metaphor and analogy in egg donation to bring out the consequences of analogical reasoning, in particular the rhetoric of reproduction through Assisted Reproductive Technologies (ART). Cellio notes that “the analogical reasoning creates associations between “fit” and “unfit” as “fertile donors” and “infertile donors.” This kind of reasoning fosters the belief that science is all-powerful and can control reproduction to create the perfect human being while eliminating the “imperfect.” However, she concludes with a warning to be wary of neo-eugenic ideals and a reminder that the foundation of human species is a varied gene pool.

Felicity Boardman in her article ‘Negotiating Discourses of Maternal Responsibility, Disability, and Reprogenetics: The Role of Experiential Knowledge’ deals with the increased

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constraints placed on the reproductive rights and choices of women with disabilities by new technologies such as ultrasound and maternal serum alpha-fetoprotein (MSAFP). She argues that experiential knowledge can be both empowering and transformative but can also introduce new dilemmas about reproductive decisions for women with genetic disabilities. This paper offers new and refined insights on the maternal responsibilities and reproductive decision making based on the *lived experiences*, which the author calls “embodied knowledge” of three women with Spinal Muscular Atrophy (SMA). It concludes with the argument that women with genetic disabilities can redefine reproductive decision-making and parenting.

Terri Beth Miller, in her paper, ‘Stalking Grendel’s Mother: Biomedicine and the Disciplining of the Deviant Body’ takes the metaphor of Grendel’s mother from an ancient tale of *Beowulf* to demonstrate the heterodoxy, aberrance and chaos. Miller illustrates how scientific metanarratives try to naturalise and neutralise the regulation of bodies through the discourses of rationality and beneficence. She examines the practices of prenatal screening and diagnosis. Applying the Foucauldian framework of disciplinary processes, she observes that these technological interventions are bound in a complex network of biomedical discourses and clinical praxis, in which contemporary modes of reproduction are increasingly imbricated in an aggressive effort at communal self-definition through a parsing of the boundaries of the “human”. She takes the Walker/North controversy that poses a dilemma of what Ruth Hubbard (2006, p.93) phrases, “Who should and who should not inhabit the world.” This debate gets intense when a woman with disabilities gets a positive genetic diagnosis for her prenatal test. It puts women’s reproductive decision-making in a complex web of biomedical and socio-political discourses.

Cynthia Lewiecki-Wilson, in her essay, ‘Uneasy Subjects: Disability, Feminism, and Abortion’ deftly interweaves two social constructs *vis. Disability and Gender* with the rhetoric of reproduction and the debates between pro-choice and pro-life camps. In the process, she traces the common history of the disability movement and feminism as both persons with disability and women have experienced different forms of exclusion and oppression. One of the common threads between the arguments of these groups is to gain autonomous subjectivity through access to reproductive control. The author suggests that these groups build networks of interdependency to foster diverse freedoms, embrace differences, and promote justice (Lewiecki-Wilson, 2011, p.77).

**Part 2 Refusals: Contesting Diagnoses and Cultural Scripts** highlights the power of stock stories that enforce cultural attitudes, identities and practices. The four contributions demonstrate the possibility of developing agency. The authors counter the dominant narrative against women with disabilities who have children. They also provide alternative ways of mothering which question the familiar themes of strength, able-bodiedness and discipline-as-care in medical discourses (ibid, p.79).

Samantha Walsh, in her paper, ‘What Does It Matter?: A Meditation on the Social Positioning of Disability and Motherhood’ explores what it is about disability that unsettles conceptions of motherhood within contemporary society.

Kristin Lindgren’s *lived experience* narrative, ‘Reconceiving Motherhood’, is a timely and immensely enriching read as it addresses the visual and cognitive dissonance when one
encounters disability and maternity in the same body. She attempts to understand how visible evidence of maternity overshadows signs of disability and how positive cultural associations with motherhood often neutralise the negative associations with disability. She problematizes these complex associations to redefine or reconceive motherhood as she opines that “Disability highlights the physical demands of motherhood, but it also engenders creative solutions.” She argues for display of private negotiations with disability and motherhood in public spaces of art, literature, and policy.

Abby Wilkerson, in her narrative, ‘Refusing Diagnosis: Mother-Daughter Agency in Confronting Psychiatric Rhetoric’, observes that Disability Studies and Gender Studies can be enriched by exploring the significance of refusing diagnosis. Wilkerson highlights how psychiatry becomes the enforcer of “compulsory able-bodiedness” and shows how mothers are often conscripted into enforcing it. She also questions the medical rhetoric through her daughter’s treatment at a mental hospital where her refusal to subject her daughter to certain tests and tasks becomes problematic. As she observes, “Interactions between doctor and patient/family are framed as a process of mutual exchange and persuasion that facilitate informed decision making and patient and parental consent, but in reality such a severe imbalance of rhetorical power exists that a context of coercion is created.” She emphasises the need to open up rhetorical spaces for replying to medical discourse to authorise ourselves to avoid some dangers of diagnosis which can endanger selfhood and agency.

Julia Miele Rodas, in her essay, ‘Diagnosable: Mothering at the Threshold of Disability’, deals with “how to locate, talk about, and live with ambiguous disability identity”. She explores through her own narrative of ‘ambiguous self’ as a mother of children’ with a proposition to ‘diagnosis’ in which she acknowledges and contests a range of perceptions on the merits and demerits of seeking a diagnosis as disabled. She concludes with refusing the diagnosis, “I embrace an undisciplined space, rejecting the confinement of diagnosis and thus choosing to challenge the narrowing definition of human ‘normalcy’” (Rodas, 2011, p.126).

Part 3 Narrativity and Meaning-Making: Rewriting Stories of Mothering and Disability recaptures stories of mothering and disability. Narratives constitute values and ways of understanding and living in the world. The contributors suggest that rewriting familiar narratives can have material consequences.

Linnéa E. Franits, in her narrative, ‘Mothers as Storytellers’, challenges the bi-directional narrative construction of disability and motherhood. She convincingly displays the changing story of motherhood with the presence of disability in new-born children.

Rachel Robertson, in her creative narrative, ‘Sharing Stories: Motherhood, Autism, and Culture’, proposes to consider disability as culture weaving, a multifaceted web of stories as she puts, “I tell my story because becoming a mother has taken me to places I never thought I would visit. I’m not talking about places that mothers go or places that mothers of a child with a disability go; I’m talking also about visiting another culture, one that is profoundly challenging, even frightening, to me, but also illuminating and remarkable.” She concludes the story of stories with the hope to bring cultural change and social inclusion.
Heather Kuttai, in her personal daily journal, ‘Nurturing the Nurturer: Reflections on an Experience of Breastfeeding, Disability, and Physical Trauma’, opens up about the various shades of emotions and experiences she goes through during pregnancy and childbirth amid her multiple back surgeries. The narrative of pain and healing that brings forth the value and agency that a disabled mother gains through breastfeeding her child is a humane read.

Suzanne Bost, in her essay, ‘Vulnerable Subjects: Motherhood and Disability in Nancy Mairs and Cherrie Moraga’ tries to explore the alternatives to self-reliance. She analyses two autobiographical narratives to understand the cultural contingencies of corporeal ideals that enable us to imagine “other” viable ways of being (Bost, 2011, p.165). Although this essay problematizes the ideals held by American culture, they can be applicable to any society that thrives on norms of “health” and “fitness”.

Part 4 Reimagining Activism: A Politics of Disability and Mothering aims to unravel the complexities of social activism. The nature of activism is mixed with the awareness of a situated politics. The contributions inform how mothers learn to advocate for social change involving better care for loved ones and awareness of the lives of those with disability. This section has four papers which explore the complexities of the middle ground in the work of activism.

Corinne Manning, in her essay ‘From Surrender to Activism: The Transformation of Disability and Mothering at Kew Cottages, Australia’ demonstrates how an institution can be transformed into a place of caring and empowerment. Parallels of Kew Cottage can be found in India where mental illness is so stigmatised that families abandon individuals at institutions even after they are cured. These long-stay patients can be integrated into inclusive and community-based living.

Merilyn Dolmage, in her candid narrative ‘History Examined: One Woman’s Story of Disability and Advocacy’ talks about how advocacy by one family can lead to community support and systematic change. This essay is unique in that it also considers fathers’ role in mothering.

Whitney Jones-Garcia, in her personal journal ‘My Mother’s Mental Illness’ gives an account of the role reversal of the traditional mother-daughter relationship. Jones-Gracia may have used a pseudonym but she accurately identifies the challenges and fears of hospitalizing her mother and difficulties of not doing so. Many of us who have had to take this difficult call can relate to these challenges and fears. However, she unravels the inadequacy of public health care system, which fails to meet the needs of people with severe mental illness; and hence she places the responsibilities of “caring” on family members.

Elizabeth Metcalf, in her essay ‘A Schizo-ly Situated Daughter: A Mother’s Labor’ exemplifies the mother-daughter relationship of committed care. Metcalf beautifully illustrates the multiple roles her mother performs to care for her which could not be performed by others.

Abby Dubisar, in her essay, ‘Motherhood and Activism in the Dis/Enabling Context of War: The Case of Cindy Sheehan’, analyse the use of disability rhetoric to establish peace by

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American peace activist Cindy Sheehan. This essay is interesting because of the way Sheehan concretises the emotional pain of losing her soldier son in war as a physical disability and then uses this metaphor of disability to speak out against the war. Dubisar analyses the benefits and costs of Sheehan’s rhetorical strategy.

**Part 5 Multiple Identities, Overlapping Borders** probes identity as a contested concept. The contributions explore the tensions of identity at the intersections of disability and mothering.

Julie Maybee, in her essay ‘The Political is Personal: Mothering at the Intersection of Acquired Disability, Gender and Race’ brings out the interplay of multiple identities. Having been in an interracial relationship, Maybee understands the social construction of disability and makes sure her daughter (who experiences a disability) negotiates the various cultural attitudes about disability, race, and gender.

Julie Minich’s rereading of Moraga’s play through disability studies lens in ‘You Gotta Make Aztlan Any Way You Can: Disability in Cherrie Moraga’s Heroes and Saints’ provides a critique of heteronormativity and shows how disabled body redefines nationalism.

Denise Cordella Hughes-Tafen, in her essay ‘Intersecting the Postcolonial Mother and Disability: A Narrative of an Antiguan Mother and Her Son’ examines the history of and attitudes toward disability in the Caribbean. Hughes-Tafen shows how mothering a child with autism affects a woman’s position in society and how a woman’s position in turn has an impact on her mothering choices.

Shawn Cassiman, in her essay ‘Mothering, Disability, and Poverty: Straddling Borders, Shifting Boundaries and Everyday Resistance’ brings forth the narratives of disabled single mothers living in poverty who resist dominant social constructions of “bad” mothers. This highlights the impact and stigma attached with disability and the failure of welfare reforms. However, it also show the dedication of all women who opt for mothering in such a situation.

Although most of the essays in this book are in the context of the US, the personal narratives (which are the main strength of this mammoth compilation) can find resonances in developing countries. This book with its unique divisions, which range from personal narratives of resistance to neo-eugenic technological intervention, refusing diagnosis, meaning making, to redefining activism is an important bridge between the two social constructs vis. disability and gender. Researchers and scholars who work on the intersection of these two social constructs will benefit immensely from this book.