



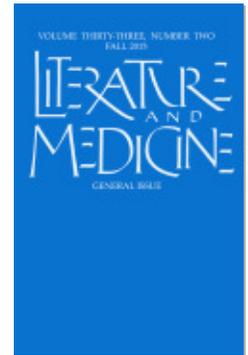
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Articulations of Care: Motherhood, Memoir, Disability

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claims, and that hoarders will learn the history of those individuals who framed their identity.

NOTES

1. "IKEA Lamp," 0:50 – 0:57.
2. Quoted in Herring, 138.

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"IKEA Lamp." YouTube video, 1:00, posted by Firat Yildiz, September 14, 2005. www.youtube.com/watch?v=I07xDdFMdGw.

Patrick W. Moran

Articulations of Care: Motherhood, Memoir, Disability

Rachel Adams. *Raising Henry: A Memoir of Motherhood, Disability, and Discovery.* New Haven, CT: Yale University Press, 2013. xii + 258 pp. Hardcover, \$26.00.

Donna Thomson. *The Four Walls of My Freedom: Lessons I've Learned from a Life of Caregiving.* Foreword by John Ralston Saul. Toronto: House of Anansi Press, 2014. 285 pp. Paperback, \$19.95.

Stories of health, illness, and ability often speak to the overlaying of political and personal spheres of experience. The purpose and providence of such representations motivates much scholarship in the field of health humanities, especially in critical explorations of the apparent transparency of first-person or non-fictional writing. Is the memoir's aim to recount the writer's own narrative of patienthood? Is it to instruct a reader's navigation of similar experiences? Is it to indicate the need for social and political change—or even to agitate for them? This genre's strongly purposive quality is amplified in the case of the family or parent memoir, an increasingly prevalent kind of life writing primarily focused on the experience of parenting a child with disabilities. Beginning with chronicles including Jane Bernstein's *Loving Rachel: A Family's Journey from Grief* (1988) and Michael Bérubé's *Life As We Know It: A Father, a Family, and an Exceptional Child* (1996),

the parent memoir has recently flourished and consolidated around its own discernible conventions, especially the evolution of parental grief into advocacy for a non-medical or social model of disability.

Another critical feature is the parental memoir's invocation (and often discussion) of the ethical conundrums of representation and consent. As Alison Piepmeier and others have observed, the parent memoir presents an especially challenging literary genre given its unsettled relationship to the aims and values of disability studies.¹ It is difficult not to think of the parent memoir as the material outcome of an inescapably utilitarian calculus, since its publication must in some sense outweigh the medical-ethical values of confidentiality, privacy, and the autonomy of its (often child or adolescent) subject. For readers interested in disability's situation within studies of literature and medicine, this reality connotes a duty to answer: Why write a parent memoir? Why read it? And most urgently in the case of the memoir inspired by the child with disabilities: who benefits?

Rachel Adams and Donna Thomson have recently published memoirs that provocatively engage these questions. In *Raising Henry*, Adams (a professor of English at Columbia University) chronicles the first three years after the birth of her son with Down syndrome. Thomson, who spent much of her life in the Canadian Foreign Service, writes in *The Four Walls of My Freedom* of her son Nicholas who was born with cerebral palsy and is now in his mid-twenties. Putting aside their differences for a moment, these eminently readable memoirs are also striking for their shared aims, textual strategies, and even narrative episodes. Both authors recount the shock of their child's diagnosis and the trauma of improperly inserting an infant's feeding tube. Both describe their negotiation of resource-strapped services and rally hard against the tragedy narrative of disability. The loneliness of motherhood, exacerbated by callous medicalized and social isolations imposed upon each author's child, is matched by episodes of profound contentment and pleasure; both Adams and Thomson describe touching moments of shared intimacy involving the ritual of baking and eating birthday cake with their sons, and indicate their appreciation for past memoirists (including Bérubé, Eva Feder Kittay, and Emily Perl Kingsley) whose experiences parenting children with disabilities amount to an activist-intellectual community and virtual caregiver network. By testifying to their authors' multiple postpartum transformations of identity, *Raising Henry* and *The Four Walls of My Freedom* are worthy additions to the parent memoir genre. Their value is especially apparent in the distinct ways Adams and Thomson apply the insights of the humanities to

reimagine care as a deeply embodied yet textual act, in which the literary imagination becomes a crucial facilitator of care for the child born with disabilities.

Raising Henry is born out of an almost improbable kind of coincidence. Adams's first scholarly book, *Sideshow USA: Freaks and the American Cultural Imagination* (2001), examined disability's enduring relationship to the nineteenth-century medicalized sideshow spectacle of freakdom; years later, Adams recounts how the post-birth revelation of her son's Down syndrome summoned disturbingly cognate ideas from health practitioners, family members, and even academic colleagues, who often viewed Henry either as a genetic curiosity or through the moralizing gothic lens of the "monstrous birth" (14). Adams's literary training prepares her for, but cannot protect her from, the academic profession's manifold hostilities toward physical and especially cognitive disability. In one unnerving anecdote, Adams finds herself, Henry in arms, at a colleague's baby shower and suddenly face-to-face with another scholar famous for her decision to have a late-term abortion because the fetus had Down syndrome. In such episodes, cerebral abstractions crash into corporeal realities. "Standing there in the doorway . . . I felt like I was part of a bad metaphor. Together, we embodied all of the unknowns expectant parents just can't think about" (102).

Raising Henry zeroes in on the blurred literal and figurative eugenic thinking that continues to inform expert accounts of disability. Adams's interweaving of scholarly research in the humanities with her own experience of raising Henry skillfully demonstrates the living legacy of medical history in contemporary cultural valuations of disability. *Raising Henry* is at its bravest when it indicts the unspeakable intolerance for cognitive disability that underpins academia's lofty, if shallow, liberal values. Alongside her condemnation of academia's ingrained ableism, Adams can be startlingly frank about her own ugly feelings too. The book opens with her recollection of a particularly agonizing episiotomy, a powerful but brutal prelude to the remembered exhaustion of new motherhood, her first-born's preference for another parent and, given Henry's intensive therapy schedule, the erasure of uninterrupted research time. Many of these moments will be legible as common if not universal struggles of parenting; others may be unfamiliar, even bizarre, to readers unfamiliar with the lifestyle afforded to certain echelons of the professoriate. Yet Adams's early, dispiriting lament that Henry will probably never share her own deep love of literature is countered by her later admiration of her son's own readerly tastes and capabilities: "Unlike his mother, Henry has no problem with endings And

so, in the spirit of Henry, who clearly knows that endings are also about new beginnings, I've decided to close this chapter of our story with the words I know he can read. THE END" (252).

Since its publication, *Raising Henry* has provoked debate concerning 1) the extent to which the author's socioeconomic privilege limits the book's generalizability, and 2) the relative weighting of Rachel Adams's story with that of Henry's. These are inevitable—but easy—objections to *Raising Henry* and the parent memoir more generally. A more expansive critical assessment would involve reading Adams's book in light of its evident links to narrative medicine. Readers of this journal will be familiar with the relatively recent practice of placing personal narratives at the center of medical care, and at several points Adams explicitly refers to personal exchanges with her colleague Rita Charon, physician and founder of Columbia's Narrative Medicine program and past editor of *Literature and Medicine*. Adams's brief, lyrical personal interludes on the meaning of a crushed snail, the eating of meat, or the discovery of her mother's journal ask readers to consider why someone, why anyone, might turn to writing to honor the stories of illness. "I started to see my writing not only as a way of capturing the particularities of my own experience but as a way to . . . talk back to the doctors and researchers and anyone who went around spouting outdated and incorrect information about Down syndrome" (115). As Henry enters toddlerhood, Adams begins to re-deploy her qualifications as a literary scholar to tell her parenting story to medical students and residents, for whom the reality of profound time-pressure presents a real obstacle to placing stories at the center of health care. It's therefore appropriate to ask: does *Raising Henry* bring premature closure to Henry's story? Probably, but Adams's subsequent writings in various media outlets reflect Henry's life beyond this memoir. So long as readers appreciate Adams's parenting experience in *Raising Henry* as one bright point in a constellation of disability stories, hers certainly deserves to be shared.

If *Raising Henry* restricts its temporal scope to Henry's birth and early childhood, *The Four Walls of My Freedom* is remarkable for its various modes of sustained temporal attention. Donna Thomson, a Canadian disability activist, writes a rich but precise account of Nicholas's life from birth to adulthood, which includes considerations of disability activism's relationship to older age (a largely neglected intersection), and even the ways in which familial happiness might be meaningfully indexed and monitored over time. Her lucid engagement with political philosophy indicates how the literary imagination can

ignite and inform health policy, and the book's literary appeal is further manifest in its foreword, written by author, essayist, and president of PEN International John Ralston Saul. Where *Raising Henry* employs the therapeutic tenets of narrative medicine as a conceptual framework, *The Four Walls of My Freedom* is rooted in Thomson's desire to enact Amartya Sen's Capability Approach as a model for living with disability. Sen's approach, originally formulated as a revision to traditional welfare economics, attempts to articulate how deeply disenfranchised lives may nevertheless have access to a state of justice that recognizes the highly personalized nature of wellbeing. Serendipitously, Thomson's family is posted to the United Kingdom, where she creates the occasion to test her hypothesis with Sen himself (Thomson, who is not an academic, charmingly describes her hard-fought meeting at Cambridge as "the hottest date of my life" [41]). Sen's personal endorsement of Thomson's capability-inspired model for disability gives rise to *The Four Walls of My Freedom*, a book that exemplifies how the methods and materials of the humanities—literature and philosophy especially—can be used to make better sense of a world more used to belittling their value.

The literary effects of Thomson's memoir result from its expert use of textual assemblage to assert and defend Nicholas's personhood against the deeply ableist assumptions of educators and health professionals (perhaps some readers as well). Multiple color photographs, data charts, and bullet-point lists appear alongside personal anecdotes, interviews, and essay excerpts: a collection of texts that reflects Thomson's multilayered attempt to speak with, rather than for, Nicholas and the care network he is dependent upon. But this memoir's thoroughly paratextual strategy also reflects the burdensome demands of institutions that oblige caregivers to produce convincing, rhetorically guided dossiers as a humanizing index of their child's care needs and rich interior life. In one Kafkaesque moment, Thomson is accused by Social Services of overmedicating Nicholas during a trip to see his idol, wrestler Stone Cold Steve Austin: "I was being investigated as a mother with intent to harm, if not kill, her child. A sense of dread, fear and helplessness oozed its way into my thoughts and dreams. I worried constantly that they might take not only Nick, but also [Nick's sister] Natalie away from us. It was ironic, I thought, that my greatest fear had been Nick dying" (159). Readers later learn that Thomson is fully exonerated from the charges after an extensive administrative examination. One wonders how less bureaucratically savvy families would fare in similar circumstances.

Perhaps to preempt such criticism, Thomson regularly juxtaposes her own caregiving experience with that of other parents of children with disabilities, including Robert Latimer (convicted of second-degree murder in the death of his daughter Tracy) or the parents of Ashley X (who successfully sought to have their daughter undergo growth attenuation surgery to enable them to care for Ashley at home). In the hands of another writer such comparisons might seem unpalatably self-serving, but throughout *The Four Walls of My Freedom* Thomson sincerely acknowledges the profound ethical and practical complexities of giving and receiving care, while remaining unswervingly committed to the right of all persons to live long lives in a state of maximum capability.

It is this understanding of disability through a life course perspective that makes *The Four Walls of My Freedom* an especially important book. Thomson's activism is motivated by a clear-eyed view of her own aging, an unshrinking attitude to mortality that underpins this memoir's argument for the need to align disability with age studies activism. Longer life, of course, is a marker of the tangible successes both of disability activism and geriatrics over the past few decades. Yet longer life for persons with or without disabilities is more regularly framed in terms of an economic crisis or burden, as sensationalized discussions of aging populations (the so-called "grey tsunami"), assisted and rational suicide, euthanasia, and resource allocation strongly influence media and policy-makers around the world. As Nicholas enters pre-adolescence, Thomson recalls how "the mantra of my worry, 'What if he dies?' was slowly becoming 'What if he lives?'" (47). In the midst of Thomson's discussion of Nicholas's life, a chapter dedicated to elder care insightfully discusses how organizations like Tyze and the PLAN Institute have committed to understanding vulnerability, disability, and care as shared across the life course rather than walled off to stigmatized cohorts of people. Intergenerational alliances that span age and ability are therefore key to Thomson's plan to "future-proof" Nicholas and, indeed, all aging beings (278). "This is a future we must build for everyone, including those with differing abilities. For the sake of love and decency, we must be allowed to build it" (207).

Both *Raising Henry* and *The Four Walls of My Freedom* appeal to storytelling as a means to improve the lives of persons with disabilities. In so doing, both Adams and Thomson confront the ethical and moral quandary of writing about the experience of a disability that both is and is not theirs. The intensely intersubjective realities of caregiving are thoroughly apparent in the case of the parent memoir.

Rather than reading such writings as more or less successful feats of (mis)representation, I see more value in approaching the parent memoir as what disability scholar Rebecca Garden has recently described as *articulations* of experience. Derived from Donna Haraway's discussion of the fraught politics of representation (which generally confers troubling or simplified accounts of narrative authority or the conditions under which one might speak for another), articulations, by contrast, involve an especially conscientious regard for the leaky singularity of one's "own knowledge and agency, as well as the conditions of representation at work in any given narrative, for example, revealing the social interests embedded in textual representations, such as the conventions of narrative and the pressures of the book market on published accounts of chronic illness and disability."² Parent memoirs present an ideal opportunity to examine the decentering potentiality of articulations as an alternative to the somewhat blunter (because well-used) critical tool of representation. For those interested in the question of how and why the literary imagination infuses matters of health, illness, and ability, Thomson's and Adams's respective articulations are required reading.

NOTES

1. See Piepmeier.
2. Garden, 4.

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