

MEDIA REVIEW: A Critical Review of Ian Brown's *The Boy in the Moon*

This paper is a review of the book: *The Boy in the Moon*. It is a memoir written by Ian Brown, a Canadian author and journalist, about his journey of raising his son, Walker, who was born with an impossibly rare genetic mutation called cardio-faciocutaneous (CFC) syndrome. Throughout the book, Brown describes vividly the minute details of the mundane but crucial daily routines of caring for Walker, which provides readers with a glimpse of what it is like for some parents to care for a severely disabled child. However, he very quickly redirects the reader away from focussing only on the caregiving tasks: "If anything, that's the easy part. The hard part is trying to answer the questions Walker raises in my mind every time I pick him up. What is the value of a life like his?" (p. 3).

The central focus of this book is Brown's search for the meaning in his disabled son's life. In his quest, Brown met with different medical experts, talked to other parents caring for children with CFC, and explored the L'Arche model of community living for the disabled. These encounters forced him to question his own values and beliefs, the science and medicine behind the disorder and how little is known about it, the inadequacy of the Canadian healthcare and social service system and its failures to support families caring for children with disabilities. More importantly, these encounters continuously circle back to Brown's question of the value and meaning of people like Walker in our community. It is this very question on which I will focus my critique.

Before I proceed, let me first acknowledge Brown's contributions. Brown's book garnered much applause and touched many hearts (The Canadian Book Review, 2010; Cooney, 2010; Nicol, 2010; Todd, 2009; University of Toronto Magazine, 2009). Not only did Brown's generous and honest sharing of his personal struggles and pain validate the experiences of many other parents of disabled children, he also asserts that what causes parents to feel guilty and desperate – so desperate that the thought of killing himself and his son crossed Brown's mind – is actually a structural problem. Brown soundly exposes the flaws in what he understands to be a pathetically lean public support system in this quotation: "The net result of this negotiating was an uneven, secretive, unpredictable game that rendered the parents of a disabled child at once anxious and grasping, as well as pathetically grateful for anything they were eventually awarded" (p. 83). Indeed, Brown builds a convincing case that the government and our society have abandoned these children and that there is the need for the government and the community to provide more public support to families caring for a disabled child.

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Putting these accomplishments aside, I want to point out and engage with what I feel to be one major weakness in Brown's book – his failure to challenge the taken-for-grantedness of the western conception of "cognitive ability" and its role in determining what counts as valuable human existence; more precisely, in determining what counts as being human. In his asking of the question, "What is the value of a life like Walker?" Brown is replicating the dominance and hegemony of pervasive ideas around "cognitive ability" and "normalcy," thereby denying the value of Walker and persons like him as human beings. There is no doubt that Walker is leaving an imprint on Brown's life as he points out, "Walker showed me ... what I would never have seen without him – his capacity to make a passing moment memorable, and my capacity to appreciate its significance" (pp. 265–266).

Brown does contend that people like Walker have a purpose in our evolutionary project: "The purpose of intellectually disabled people like Walker might be to free us from the stark emptiness of survival of the fittest" (p. 234) (Cooney, 2010). And even though it seems not to be Brown's intention to deny the value of Walker and persons like him, I am arguing that the problem lies in the hidden assumptions behind the very action of his continuous questioning of the value of Walker's life, and in his emphasis on certain methods as the means of answering this question.

Why Ask What is the Value of a Life Like Walker?

In posing this question, it is assumed that some lives are more valuable than others. If all lives are of equal value, then there is no need to ask this question at all, is there? To me, this question is similar to a white Canadian asking a racialized Canadian "where are you from?" What initially appears to be a benign question is driven by the hidden assumption that the racialized Canadian is different, could not have been born here, and is, therefore, not considered to be a "normal" Canadian. Similarly, in repeatedly asking the value of Walker's life, it is assumed that Walker *is* different and that this difference is what renders him less "normal," hence less valuable. Walker and others with disabilities are being constructed as "them" in contrast to

"us": where the "us" is the unspoken standard or norm against which people with disabilities are being measured. However, in Brown's book, this normative subject is invisible. Nowhere in the book does he speak about what is normal. It is this invisibility that serves to reinforce the hegemony of "normalcy."

Conversely, Walker's apparent (to Brown) "abnormality" is highly visible, and oftentimes is portrayed in the book as negative; "I hate his room because it feels like an out-of-date museum, a place that, like my son, rarely progresses" (p. 17). Brown uses phrases such as "lost and broken," "unfixable," and "human anomaly" to describe Walker, and it is clear from his language and descriptions of his son that Brown sees Walker's condition as something needing to be fixed. This perception aligns with the diagnostic-medical approach that understands disability as a "defect" that needs to be corrected or eradicated. Those who cannot be cured continue to be understood as "deficient," or as a "deviant" functioning outside of socially acceptable norms (Gilson & DePoy, 2002). It is, thus, Walker's visible "abnormality" that renders him the "other" and therefore less valuable. Consequently, the reader comes to learn of Brown's hope that the therapist can cure Walker and "send him on his way to a normal life" (p. 19), and of his disappointment with the field of genetics and with medicine more broadly when he found out there was nothing the medical profession could do to cure Walker. Brown felt that he had lost his son. While it seems understandable that one would grieve over a significant loss, I wonder why it is that the incurable nature of Walker's condition is understood to be a loss to begin with. In constructing Walker's unfixable condition as a reason to grieve, Brown once again perpetuates Walker as the visible – and undesirable – "abnormal."

Brown seems to be unaware of his own assumptions about what is considered to be "normal." For Brown, to be "normal" is to be like him: to be able to speak, to be independent and, more importantly, to be able to have thoughts and an inner life – something he assumes Walker does not have. Brown longs for his son to have an inner life: "What I cared about was whether he had a sense of himself, an inner life. Sometimes it seemed like the most urgent question of all" (p. 48).

Why is it so important to Brown that Walker have an inner life? We can find the answers from this poignant quotation, “Sometimes watching Walker is like looking at the moon: you see the face of the man in the moon, yet you know there’s actually no man there” (p. 3). What he appears to be saying here is that while Walker possesses the physical form of a human being, there is nothing inside – Walker is no more than an empty shell. The implication then is that simply having the form of a human being does not automatically grant Walker membership in the human race. In order to claim membership, Walker needs to demonstrate he also possesses an inner life; an inner life marked by the intrinsic psychological capacities of rationality and autonomy (Kittay, 2005). This is not surprising given we live in a world where “beauty may charm and physical prowess may awe, but intellect rules supreme” (Kittay, 2001, p. 563). If, as one can infer from this book, Brown understands the capacities of rationality and autonomy as the foundational qualifications for membership as human and for the right to claim equal respect and dignity in this community, it makes sense that proving (to himself) the existence of an inner life in Walker is so important to Brown. But is having the competencies of rationality and autonomy the only qualification that defines us as human, and as deserving of the right to equality and inclusion? Even if it is, how does Brown really know whether Walker has an inner life or not?

Ways of Searching for the Value of Walker’s Life

If only Walker had the ability to speak, then, Brown argues, it would be pretty simple to figure out whether Walker has an inner self or not. But Walker does not speak, at least not in the way that Brown and “normal” human beings do. In the absence of speech, Brown describes throughout the book his search for signs that Walker has thoughts, intentions, and desires that will prove the presence of an inner self. He describes moments when he sensed this inner life was affirmed (for example, when he felt that both he and Walker enjoyed the bath, or when they used clicking to communicate). However, he very quickly determines this to be absurd and irrational thinking on his part. He asks, “But did he feel anything? Did the outline of

a boy I saw beneath his stolid surface, beneath the dead-calm pond of his mind, actually exist? Or was it wishful thinking?” (p. 38).

It seems that Brown puts more value on “spoken language” than on other potential indicators of ability and presence; the ability to speak a particular language is understood as a sure sign of the expression of an inner self even if it is simply a repetition of words from the normative language. This is most obvious in his encounters with Cliff, another child with CFC, about whom Brown writes that, “their language is more borrowed than self-generated. But at least it is language, proof of an inner life” (p. 124). I find this emphasis on spoken language especially interesting when contrasted with the different understandings expressed by people with disabilities themselves. For example, Amanda Baggs (2007) – a non-speaking woman who self-identifies as having autism – would argue the opposite and describe the ability to speak a particular language as a more limited set of responses for interacting with the world around us. Baggs’ critique of the valorization of the spoken word raises questions about the social construction of what counts as intelligence, personhood, language, and communication (Thomas, 2004).

In addition to the belief that the possession of “spoken language” is proof of an inner self, Brown also relies on medical experts and science as other valid ways to seek to confirm that Walker has an inner self, and is, therefore, a valuable human. Even after talking to philosophers and to members of the disabled community, hearing from them that there are alternative ways to view and understand ‘disability’, Brown still resorts to a brain scan, hoping that it will reveal just what is (and is not) inside Walker’s brain. Unfortunately, for Brown, the brain scan fails to reveal any more information than he already knew:

The fancy pictures told me less than I could figure out from ten minutes in his [Walker’s] company, and there was no fine grade to these pictures, no subtlety. It was a technical report on the hardware, not that it wasn’t grave enough (pp. 279–280).

As much as Brown comes to challenge the authority of science and to resist the geneticist’s reduction of his son’s life “to a typing error in a

three-billion-long chain of letters, to one dinky nucleotide" (p. 272), he still does not believe and trust his own interactions with Walker. Instead, he continues to put his faith in the results of brain scans and science and keeps pressing the question, "Without a knowable brain, was Walker a knowable boy? If he wasn't knowable, what was his value?" (p. 282). As Brown continues his quest to understand Walker's value, he eventually turns to Jean Vanier, the founder of the L'Arche model of intentional community for people with and without intellectual disabilities. Vanier suggests that the value of Walker – or any person – is in the act of being; so, when Walker clicks and Brown clicks back, they are in communion and it is, in part, this which indicates Walker's value. Kittay (2005) similarly observes that "relational properties are generally not relevant" (p. 107) in societal definitions of the nature of personhood. I believe this is the very reason why Brown found "comfort in what Vanier said about Walker's value, and yet the effort of believing it was sometimes exhausting" (p. 221). As long as Brown fails to see how pervasive is the power of the givenness of the hegemony of normalcy and rationality, his struggle persists, and his journey in search of Walker's value in life remains in vain.

Connecting with the Fears of the Audience

In this book, Brown is portraying a tragedy – a sad story. In representing Walker as a "human anomaly" and his story as one of "difference," he is inviting the audience to be sympathetic towards Brown, Walker, and the rest of his family. And, at the same time, he is connecting with the mainstream audience's fear of this particular tragedy – the burden of caring for a disabled child.

I have mixed feelings about this book. While Brown provides a clear and strong critique of the failure of the healthcare and social service system to support families caring for disabled children, I struggle with many other messages in this book. In addition to those I have already articulated, as a racialized feminist, I have trouble appreciating Brown's humour in noticing the cleavage of Walker's worker, or his calling the baby-sitter "one-eye." I also find it offensive to compare Walker to the "strange-

ness" of a transgender person, as they, too, are only strange when the "norm" against which their difference is being measured is taken-for-granted and not interrogated. Also, as someone from a working class background, I can't help but find Brown's worries about his finances and a retirement that does not include having a cottage to be like a rich boy whining. I am not denying the hardship and the financial difficulties he is experiencing – I think that sometimes the state is not very lenient towards the middle class and am well aware of the financial burdens for parents of a child with a disability effected by ineffectual support systems – but at least those in the middle class have more to fall back on when compared to those from the lower class (and I have not even touched on the compounded challenges of the multiple social characteristics of parents such as ethnicity, immigrant status, etc).

Yet, what troubles me most is Brown's heavy emphasis on Walker's deficits: his lack of language skills and cognitive ability as defined by conventional standards. As Kittay (2001) contends, a focus on the limitations of the cognitively impaired only sets them "outside liberal definitions of personhood and citizenship that are fixed on intellect, independence, and productivity" (p. 560), and thus deprives them of their entitlements to resources as equal citizens. I would have enjoyed this book more had Brown been more positive about the "small" pleasures and joys of being with Walker, and focussed and validated more of the relational aspects of being human, instead of naming such as the "reckless faith" of the religious "zealot" (p. 38). It is through the incorporation of the relational aspects of being human that we can broaden our conception of personhood and citizenship, and see the beauty and fullness of being "human." In addition, I believe that had Brown spent more energy interrogating the location in which he stands and writes, I would have had more appreciation for, and less of a struggle with, connecting to this book. This book serves as a reminder that no matter how good our intention, how much we love the subject of our gaze, it is very possible that we will reproduce their subjugation if we are not aware.

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