

# BOOK REVIEW

## ELIZABETH BARNES: *THE MINORITY BODY: A THEORY OF DISABILITY* (2016)

Charles Ngwena\*

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Oxford: Oxford University Press 1-197; i-xii. ISBN 978-0-19-873258-7

### 1 Introduction

Regardless of the cultural setting, it is hard to find consensus on how we understand or, much less, ought to understand disability. Within as well as across cultures, there are different epistemologies of disability, each with its own cultural history and normative implications. Some epistemologies are built on culturally-embedded assumptions of disability as something explicable primarily in terms of bodily and mental impairment which is intrinsically bad. Others seek to counter this deficit approach in a variety of ways. Furthermore, disability epistemologies forever are in flux rather than fixed. Indeed, part of the explanation behind the absence of a definition of 'disability' in the first disability rights-specific human rights treaty, adopted in 2006 – the Convention on the Rights of Persons with Disabilities (CRPD)<sup>1</sup> – is precisely because its architects wished to avoid dogmatism in favour of an understanding of disability which is cognisant of the contested and ever-evolving nature of disability.<sup>2</sup>

\* LLB LLM LLD; Barrister-at-Law; Professor, Centre for Human Rights, University of Pretoria.

1 GA Res 61/611, adopted on 13 December 2006, entered into force on 3 May 2008.

2 A Lawson 'The United Nations Convention on the Rights of Persons with Disabilities: New era of false dawn' (2007) 34 *Syracuse Journal of International Law and Commerce* 563 593-594.

The subject of this review – *The minority body: A theory of disability* – is a book written by Elizabeth Barnes, an American philosopher. *The minority body* belongs to the domain of discourses that seek to vigorously counter a deficit epistemology of disability built around disability primarily as a biological disorder and its medicalised imprimatur. Barnes's book is an important addition to contemporary debates on disability. Its importance does not lie in saying something entirely new about disability to contest a deficit approach to disability. Rather, it lies in giving theoretical voice to a marginalised view in disability discourses. It is a voice which is open-minded about whether disability is good or bad and, thus, leaves sufficient discursive space for conceiving disability as plenitude rather than always sub-optimal. This is an approach Barnes describes as a 'value-neutral model' of disability in which disability is 'mere-difference' but not automatically 'bad-difference'.

Barnes's central thesis or her overriding motif is neatly summarised in the following proposition which she makes in chapter 3 of the book:<sup>3</sup>

Having a disability is something that makes you different but not something that makes you worse off because of that difference. Being disabled is something that makes you a minority – it is a way of having a *minority* body.

This proposition, which speaks to the title of book, encapsulates the main claim the author attempts to theorise and substantiate through argumentation. Barnes's basic argument is that to be disabled is not to have a 'broken or defective body'; it is not something intrinsically bad or sub-optimal but rather is analogous to other minority status such as being gay in respect to sexuality.<sup>4</sup>

To appreciate the arguments in *The minority body* it is essential to begin with an understanding of what the book is *not* about, partly because 'disability' is often used as an umbrella term to encompass a multitude of disability conditions. Barnes begins by entering a caveat to limit the disability scope of her discourse. *The minority body* is primarily about 'physical disability'.<sup>5</sup> The author highlights that she does not wish to be understood as seeking to develop a discourse that addresses all types of disabilities. Behind this caveat is the author's acknowledgment of the heterogeneous nature of disability and the difficulties of developing arguments that speak for all disabilities. Thus, whilst Barnes's arguments may have relevance for other types of disabilities, such as psychosocial and intellectual disabilities, the focus of her book squarely is on physical disabilities. She underscores the fact that there is no single notion of disability regardless of the fact that people who experience disability may organise on the basis of a common experience and solidarity.

3 78 (emphasis in original).

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Another reason for limiting the scope of the book to physical disabilities is a method or theoretical approach emanating from what feminist discourses describe as 'standpoint epistemology'.<sup>6</sup> For her argumentation, Barnes mainly relies on testimonies of disabled people who claim to value having a physical disability. The author uses first-hand testimonies from individuals who have experienced physical disabilities or from disability pride movements that speak on their behalf as an essential method for persuading readers about the authenticity and cogency of her claim that having a physical disability is something that makes you different but not worse off.

## 2 Overview of the book

The introduction aside, the book comprises six chapters. In the introduction, which is substantive, Barnes explains the goal of her book, its scope, method of argumentation and theoretical leanings. Describing her theoretical approach as 'social philosophy that is heavily influenced by feminist philosophy',<sup>7</sup> the author explains her main goal as 'defending' (as opposed to advocating for the first time) a view that is already shared among disability rights movements which is that a 'physically-disabled' body is not a 'defective' body but simply a 'minority body'. She seeks to counter a culturally-dominant view of disability as a biological disorder and its deficit implications. In order to achieve her objective, the author regards it as crucial to reflect philosophically on the following questions: (1) What is disability? (2) What is the connection between disability and well-being? (3) What would it mean to say that disability is not something inherently bad or sub-optimal?<sup>8</sup> Barnes regards these issues as foundational for any disability discourse.

The introduction is also important for an attempt to clear a terminological underbrush or, at least, to explain how the terminology to describe disability is used in this book. Barnes does not attempt to find universal terminology for describing disability since it would be a futile effort as disability is contested, thus, defying universalism. She 'uses' disability in a contingent manner that is synergic with her overall 'minority body' thesis. This thesis acknowledges disability as implicating the physical body and, more specifically, bodily difference. At the same time, Barnes's thesis is neutral to disability and does not read difference as implying something inherently sub-optimal.

6 In this context, 'standpoint epistemology' means not merely the desirability but, more significantly, the necessity of building knowledge and understanding about equality norms through integrating the lived experience of those that have been at the receiving end of exclusionary social practices: A Brooks 'Feminist standpoint epistemology: Building knowledge and empowerment through women's lived experience' in SN Hesse-Biber & P Leavy (eds) *An invitation to feminist method* (2007) 53-82.

7 2.

8 As above.

For Barnes, 'disability' means 'particular bodily features or conditions',<sup>9</sup> and 'disabled people' are individuals who have such bodily features or conditions.<sup>10</sup> Her use of 'disability' deliberately parts company with deficit approaches to disability. Equally significant, Barnes's use of 'disability' is different from how the concept is used in popularised 'people first language' such as 'people' or 'persons with disabilities' which finds its formal human rights global adoption in the CRPD.<sup>11</sup> Barnes makes it abundantly clear that she is using 'disability' in a sense which approximates 'impairment' under naturalistic accounts of disability but without importing their underpinning deficit assumptions about corporeal difference. She says:<sup>12</sup>

I use the word 'disability' to refer to particular bodily features or conditions ... 'disability' refers to the physical states of bodies-to particular bodily features – my usage of 'disability' is closer to what is often meant by 'impairment' in the literature on disability ... I use 'disabled people' to refer to people who have the sorts of bodily features or conditions picked out by the term 'disability'. I use 'disabled people' rather than 'people with disabilities' because 'disabled people' mirrors our usage of other terms which pick out minority groups – for example, we say 'gay people', not 'people with gayness'.

In subsequent chapters, beginning with chapter 1, Barnes develops arguments to clarify and, more importantly, substantiate her premise of disability as bodily difference which is not intrinsically bad and is 'neutral' with respect to well-being.

In chapter 1 titled 'Constructing disability', Barnes clarifies her own social construction of disability. In addition to providing an alternative reading of disability to contest deficit approaches built around naturalistic assumptions about bodily capacity and functioning, she unpacks what is often painted with a broad brush or deliberately not given attention in the more popularised 'social model' discourses of disability, especially the version pioneered by British sociologists.<sup>13</sup> She argues that it is better to treat the 'social model' of disability not as a single epistemology but, instead, as social constructionism of disability that encompasses a 'family' of approaches that may even contest one another.<sup>14</sup> Her main contention is that the version of a social model approach which claims that disability is entirely constituted by prejudice against or lack of accommodation of persons with disabilities is inadequate, if not flawed and implausible. It is not true, Barnes argues, that all the bad effects of disability are socially mediated. Even if society were completely accepting, disability would still have dramatic effects on the lives and health of the affected individuals. To

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10 As above.

11 IK Zola 'Self, identity, and the naming question: Reflections on the language of disability' (1993) 36 *Social Science and Medicine* 167-173.

12 5.

13 M Oliver & C Barnes *The new politics of disablement* (2012).

14 25.

make her point, Barnes gives as examples disabilities that cause chronic pain; that require continued medical interventions or are progressive; and for which societal discrimination and social injustice do not hold any explanatory power.<sup>15</sup>

Barnes's criticism of the more popularised genus of the social model is not novel. Rather, it reiterates criticisms that, over the years, have come from within disability movements as well as from disability scholars, more generally. At the heart of the criticism is discontent with social constructionism which attributes disability entirely to discrimination and social injustice, but without taking full stock of the existential experience of impairment.<sup>16</sup> Critics are not dismissive of the value this type of social constructionism has bestowed on disability rights struggles, but they say it is an inadequate epistemology. They do not deny that framing disability as the effect of an ableist society has been transformative in providing the impetus for the development of a jurisprudence of substantive equality and unfair discrimination for affirming the inherent dignity and equal citizenship of disabled people. Such framing has raised political consciousness about the marginalisation and exclusion of disabled people as social oppression and disadvantage which is structural in nature and ought to place an onus on society to dismantle disabling barriers. What critics contest is the effacement of embodiment in a social model of disability which attributes *all* the disadvantages experienced by disabled people to the social environment, but without saying a word about the experience of bodily impairment. Critics, including Barnes, say this type of social model is too reductionist; it over-dichotomises impairment and disability.<sup>17</sup> By focusing on the social environment as the cause, the personal experiences (both positive and negative) of those who live with impairments are effectively silenced.

Partly against the backdrop of discontent with the adequacy of a social model which focuses only on the disabling effects of the social environment, Barnes argues for an epistemology of disability that takes impairments into account. She does not abandon social constructionism but decentres it. She describes her approach as 'moderate social constructionism'.<sup>18</sup> It is an approach to disability which is socially constructed but places a *greater* emphasis on the actual features of the body.<sup>19</sup> Barnes brings to social constructionism the visibility of the existential reality of impairments. The author puts a gloss on her approach

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16 T Shakespeare & N Watson 'The social model of disability: An outdated ideology' (2002) 2 *Research in Social Science and Disability* 9; D Anastasiou & JM Kauffman 'The social model of disability: Dichotomy between impairment and disability' (2013) 38 *Journal of Medicine and Philosophy* 441; B Hughes & K Patterson 'The social model and the disappearing body: Toward a sociology of impairment' (1997) 12 *Disability and Society* 325.

17 26-27.

18 38.

19 As above.

when she says ‘though disability doesn’t seem to be entirely explained by what disabled bodies are like, it’s also not entirely separate from what disabled bodies are like’.<sup>20</sup>

The rest of the book (that is, chapters 2 to 6) is taken up by explicating and defending a ‘value-neutral model’ of disability which is a way of seeing physical disability as not defective or inherently bad. Above all, a value-neutral model is an approach to disability which asks us to view disability without any prior assumptions. In articulating this model of disability, it is important to Barnes to draw a distinction between ‘bad-difference’ and ‘mere-difference’ and their intersection with the concept of well-being.<sup>21</sup> At the same time, the author is careful not to draw a rigid dichotomy between ‘bad-difference’ and ‘mere-difference’ as within each difference there is more than one view of what constitutes well-being. The point Barnes ultimately underscores is that ‘bad-difference’ is our ‘common sense’ epistemology of disability. It is not an objective truth but, instead, a product of socially-embedded views emanating from normative values about human flourishing which distinguish between what is normal and what is not.<sup>22</sup> According to these values, impairment which reduces ability invariably is a detraction. Thus, even if ableism were eradicated, a disabled person would still be seen by the general society as someone who is likely to have unfulfilled desires than their counterpart without a disability. Even if a disabled person were to assert the contrary and claim to value disability as an experience of plenitude, this claim is likely to be dismissed not as an objective truth but as a mere ‘adaptive preference’.<sup>23</sup>

To counter ‘bad-difference’, Barnes explains that the ‘mere-difference’ approach, which is an essential component of how the author constructs her value-neutral model, does not require us to see disability as something that is positively valued by everyone.<sup>24</sup> Equally, it does not require us to discount that some bad effects of disability are caused by societal prejudice and a lack of accommodation.<sup>25</sup> Barnes is not saying that ability is not valuable, but rather that it can be valuable without those who lack it being universally worse off and their experience of valuing disability being dismissed.<sup>26</sup> She is saying that there are some who value disability. Drawing on the work of Miranda Fricker, Barnes argues that to dismiss the experience of those who value disability amounts to both epistemic and

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21 Ch 2 especially focuses on articulating the concepts of ‘bad-difference’ and ‘mere-difference’.

22 61-63.

23 123-133. Barnes is critical of discourses of ‘adaptive preference’ she regards as speaking for disabled people from unarticulated assumptions rather than hearing their own voices, including the work of Harman: E Harman ‘I’ll be glad I did it reasoning and the significance of future desires’ (2009) 23 *Philosophical Perspectives* 177.

24 77-78.

25 As above.

26 95.

hermeneutic injustice.<sup>27</sup> It is injustice which is socially produced by a dominant epistemology of disability as a lack.

### 3 Significance

Barnes's book is a reminder that our disability debate did not end with the adoption of the CRPD in 2006. Contestation, contingency and conceptual metamorphosis are here to stay, and will continue to shape our disability discourses. As long as we are open to critical thinking and to interrogating not just prejudiced and stigmatising assumptions about disability but even progressive views about disability, including the hugely-popularised version of the 'social model' of disability, epistemologies of disability will forever be on the march.

For several reasons *The minority body* is an important book. It revitalises a marginalised epistemology of disability. It reminds us that, as we focus on implementing the CRPD to consolidate the gains made by the 'social model' largely pioneered by British sociologists,<sup>28</sup> the body still matters and should not be 'disappeared'. Whilst it is strategic to construct disability as the effect of a disabling environment, we need not efface embodiment. Impairments are real and, yet, they are not coterminous with intrinsic badness.

The emphasis of Barnes's discursive inquiry ultimately is on countering epistemic and hermeneutic justice, taking into account positionality so that we affirm the experience of each person, including those that experience impairment. The book affirms and celebrates human difference. Barnes explores the connection between disability and well-being in a manner designed to hearing all the voices, especially the voices of those who experience impairment and yet value their disability.

It is customary in a book review to attempt to find shortcomings in the subject of the review. Often the opportunity for criticism is presented when an author makes broad and sweeping claims. My sense is that Barnes meticulously avoids these common pitfalls. Therefore, Barnes's book does not easily provide one with a vantage point for criticism unless we are asking her to write a book she did not intend to write. From the very outset, Barnes is careful about making broad claims, including limiting her inquiry to physical disabilities rather than attempting to speak for all disabilities. The book is a work of admirable scholarship.

27 69-171; M Fricker *Epistemic injustice* (2007).

28 n 13 above.