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# Book Review: *Camouflage: The Hidden Lives of Autistic Women* by Sarah Bargiela

Sara M. Acevedo
*Miami University, Ohio*, acevedsm@miamioh.edu

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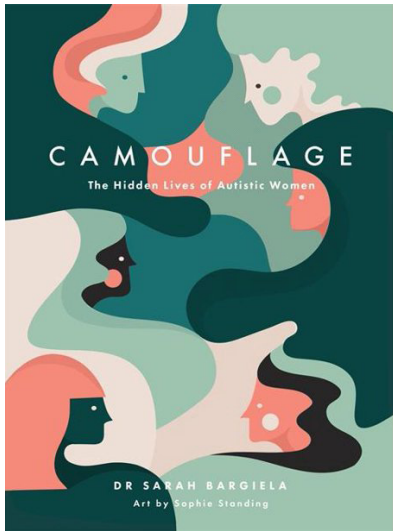
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The Autistic Community Lydia X.Z. Brown

# Book Review: *Camouflage: The Hidden Lives of Autistic Women*

*Camouflage: The Hidden Lives of Autistic Women* by Sarah Bargiela
(Jessica Kingsley Publishers, 2019)

*Camouflage: The Hidden Lives of Autistic Women* by Sarah Bargiela (2019) is a graphic story book with colorful and engaging illustrations that offers a unique perspective of the day-to-day experiences of autistic women through the lens of an omniscient narrator, a "tour guide" named Amy. Amy was herself diagnosed at age 20 and subsequently created a forum where other women considering an autism diagnosis could ask questions, share concerns, and exchange experiences. Bargiela's rhetorical strategy affords the reader a sense of familiarity, which in turn strives to both demystify and humanize the lives of autistic women and, if expanded in scope, disabled women overall—more of this in a later section. The author's brief acknowledgments section points to this idea, as she recognizes the value of first-hand perspectives in lending complexity and depth to a subject often misunderstood and neglected.

The book opens with a brief overview of historical approaches to autism in the Westernized world, beginning with the roles of two doctors to first conduct and publish research on autism. Both Hans Asperger, a pediatrician from Austria, and Leo Kanner, a German doctor living in the United States, based their accounts and medical perspectives of autism on case studies with small groups of boys; each described their experiences with boys who behaved "in similar and unusual ways" (Bargiela, 2019, p. 1). While Kanner focused on children with "extraordinary memory for faces, names, and songs," Asperger focused on the experiences of a small group of boys who he named "little professors"

based on the fact that they did not engage in typical conversation with others and focused primarily on their individual "special interests" (Bargiela, 2019, p. 2). Asperger's influence continued well into the 21st Century, so much so that a category in the *Diagnostic Statistical Manual of Mental Diagnosis* IV was labeled after his name to differentiate "high" vs "low" functioning autism. The category has now been removed from the manual to recognize the autistic experience along a spectrum: Autistic Spectrum Disorder (ASD).

Following a chronological timeline, the author describes subsequent research on autism; this time focusing on girls "with autism." She offers a few remarks on the work of Lorna Wing, a psychologist who discussed the differences between "high" and "low" functioning autistics, establishing a gendered statistical comparison between the two. Moreover, Bargiela draws on Baron-Cohen's theory of the "extreme male brain" and Tony Atwood and July Gould's theory of "social mimicry" to further discuss the autism diagnostic gap between men and women. She highlights three main arguments here: 1) there are differences between the female and male autism phenotype, 2) women hide autism more successfully, and 3) diagnostic questionnaires do not capture female autistic features (Bargiela, 2019, p. 4-5). Bargiela then introduces the experiences of three different autistic women, Paula, Ellie, and Mimi, to more closely illustrate and effectively humanize the above categories as they manifest in each of these women's lives. She addresses restricted interests, repetitive behaviors, sensory sensitivities, mimicry, relationships, social communication, identity development, and finally empowerment.

Three important points deserve further commentary here: first, the use of person-first language—"person with autism"—is a misnomer according to a large majority, although not all, autistic activists in the U.S. In a piece from 1999, pioneering autistic activist Jim Sinclair argues that "saying 'person with autism' suggests that the autism can be separated from the person. But this is not the case"; it also suggests that "autism is something bad—so bad that it isn't even consistent with being a person" (Sinclair, 1999, para. 1-3). In like manner, a notable autistic activist, author, and attorney Lydia X. Z Brown . argues that in the autistic community (they refer here to the U.S. community more specifically),

"many self-advocates and their allies prefer terminology such as 'Autistic,' 'Autistic person,' or 'Autistic individual' because we understand autism as an inherent part of an individual's identity" (Brown, 2011, para. 3). Brown points to this difference to highlight the major role of identity development in shaping autistics' well-rounded experiences as social, cultural, and political agents. Ultimately, both Sinclair and Brown's stances argue for wholesome personhood beyond reductive pathology.

In a blog post from 2016, I offer a different, although related argument in order to historically situate different trajectories in U.S. disability politics and activism and to contextualize the changing dynamic of language use:

> Person-first language preference is common among older generations of activists who struggled intently and collectively against the medico-social conflation of disability and pathology, and the subsequent abuse of disabled people in state institutions and communities. Whereas disabled advocates, many of them emerging from the U.S. autistic movement of the 1990s, choose identity- first language [to] point to both social processes of disablement and to the belief that autism is a valid and valuable way of being in the world, as opposed to a tragic condition that needs a cure. (Acevedo, 2017, para. 2-8)

Second, and as Bargiela herself points out, "low" and "high" functioning are pathological categories that the U.S. autistic community largely rejects. Prominent autistic activist and writer Amy Sequenzia (n.d ) notes that functioning labels are "something created by non-disabled people who knew very little about how autistic brains work, who saw autistics as lesser people, and who saw the need to grade us in order to apply their wrong assumptions in an attempt to 'fix' us" (para. 1). Along similar lines, Australian autistic activist and writer Michelle Swan argues that, "labeling an autistic person high or low functioning denies that, just like any other person, autistic people are complex and nuanced and subject to the full range of variations in energy and capability at any given moment in time" (Swan, 2019). Swan assures that functioning labels are indeed reductive, and I would add dehumanizing, as they project a false understanding of the autism spectrum as a linear, unbiased, understanding of the autistic experience. In fact, the public generally imagines spectra as a straight

line between point A and point B. It is thus important to point out here that spectra are not organic phenomena. Rather, they are constructs that vary among societies and cultures and across both medical professionals and disabled people's perspectives and experiences. In short, ongoing oppressive mischaracterizations of disability result from uninformed understandings and widespread unfamiliarity with and/or willful disregard for the complexity and multidimensionality of our embodiments, our lived experiences, and the power of our own storytelling.

Ultimately, however, our cultural and political histories, the ones we weave and the ones we tell, inevitably break with and defy the normative world's ideal of a worthy and productive humanity. Along with the symbolic violence of the discursive, the material harm of these polarizing labels in the everyday cannot be understated. Externally, they enable harmful medical and so-called therapeutic interventions and/or neglectful approaches to access needs, services, and accommodations that depend on the "severity" of a diagnosis (Sequenzia, n.d). Internally, the labels polarize autistic people and reinforce a false hierarchy of human worth and value, which likely hinders the furthering of political coalitions and activism among disabled people with varying access needs.

Returning to *Camouflage*, my third point is that research zeroing on the differences in phenotype between "women and men" has benefitted some CIS heterosexual women and assisted in accessing an autism diagnosis later in life, although not for all, and not without the hurdles associated with the diagnostic gap among racialized, immigrant others—including in my case. Further, the idea of an "autism female phenotype" as necessarily different from the "male autism phenotype" reinforces hegemonic masculinity as the source and female autism a variant (Bargiela, 2019, p.5). Moreover, the idea that there are necessarily "female autistic traits" and "male autistic traits" reifies the gender binary and, in turn, makes the lived experiences and identities of transgender and non-binary autistic people invisible (L. X.Z. Brown, personal communication, April 8, 2020; see also, Davidson & Tamas, 2015; Kourti & MacLeod, 2018; Williams, 2019).

To conclude, the above commentary is meant to expand upon the value of Bargiela's account, rather than to undermine its important contribution. Due to reasons of scope and space, my intervention intends to add another layer of complexity by pointing to, although not fully addressing, the literary absence of the stories of autistic women, trans women, and non-binary people living at the intersections of race, immigration status, gender non-conforming expression and identity, and the critical issues that impact our lives. What Bargiela offers in *Camouflage* are indeed all factors that have and continue to inform the lives of autistic women, transgender women, and non-binary people, in terms of our lived embodiments as well as individual and community identity development processes. A sequel to this fun and accessible graphic story book that expands upon transgender, non-binary, and racialized identities and experiences within and beyond nations of the Global North world would appeal to a much wider audience.

This book is recommended for educators, anthropologists, sociologists, as well as those in the arts and humanities.

**Sara M. Acevedo** is an autistic Mestiza educator, action anthropologist, and disability justice scholar-activist born in Colombia. She is Assistant Professor of Disability Studies at Miami University in Ohio. She holds a doctoral degree in Anthropology and Social Change from the California Institute of Integral Studies and an MLA with a focus on Disability Studies from Temple University.

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